The Self-Management Approach of Health Education in the Treatment of Chronic Illnesses

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Abstract

Health education is essential to the successful treatment of individuals with chronic illnesses. Self-management is a philosophical model of health education that has been shown to be effective in teaching individuals with chronic arthritis to manage their illness as part of their daily lives. Despite the proven results of arthritis self-management programs, some limitations of this form of health education were apparent in the literature. The present study attempted to address the problems of the self-management approach of health education such as reasons for lack of participation in programs and poor course outcomes. In addition, the study served to investigate the relationship between course outcomes and participation in programs with the theory upon which arthritis self-management programs are based, known as self-efficacy theory.

Through a combination of qualitative and quantitative methodologies, data collection, and analysis, a deeper understanding of the self-management phenomenon in the treatment of chronic arthritic conditions was established. Findings of the study confirm findings of previous studies that suggest that arthritis self-management programs result in enhanced levels of self-efficacy and are effective in teaching individuals with arthritis to self-manage their health and health care. Findings of the study suggest that there are many factors that determine the choice of participants to participate in programs and the outcomes for the individuals who do choose to participate in programs. Some of the major determinants of enrollment and outcomes of programs include: the participant's personality, beliefs,

attitudes and abilities, and the degree of emotional acceptance of the illness. Other determinants of course enrollment and outcomes included class size and length of time, timing of participation, and ongoing support after the program. The results of the study are consistent with the self-management literature and confirm the relationship between the underlying philosophies of adult education and Freire's model of education and self-management.

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CHAPTER ONE: THE PROBLEM

Introduction

This is a study that investigates a philosophical approach to health care and health education known as self-management. Specifically, the study focuses on health education using the self-management approach with individuals who have chronic illnesses. This study is based on a variety of sources including the author's observations and clinical practice, a review of the related literature, and interviews with individuals with chronic arthritic conditions who have taken part in a self-management health education program.

Health education plays an integral role in the effective treatment of chronic illnesses. Education in the health care setting can provide the individual with the chronic illness knowledge of the disease and the disease process, coping strategies, information about available treatment options, and emotional support. All together, health education helps the individual with chronic disease to cope with consequences of their illness, which in turn can improve their quality of life and overall well-being. Furthermore, health education can empower informed decision making, promote self-care, enhance control over medical management, and reduce overall dependency on the health care system.

Traditionally, health education has occurred within a compliance model of health care. That is, the goal of "teaching" patients is to have them comply with medically prescribed treatment regimes. The compliance model of health education is

characterized by paternalism, as the underlying educational philosophy is hierarchical, authoritative, and prescriptive. Education in this model becomes the health care professional dictating information to the patient, with little thought given to the notion of open dialogue between the teacher and the learner, or in this case the health care professional and the patient.

The self-management model is an approach to health education that is increasingly preferred over the compliance model-especially for individuals living with chronic diseases (Lorig & Gonzalez, 1992). Self-management means being responsible for managing one's own health and health care. In this sense, individuals assume greater responsibility for all aspects of care. In the self-management model, the relationship between the patient and provider requires active participation of both parties. The self-management approach promotes an equalization of the power distribution between the health care professional and the patient. As a partnership is developed, the patient is empowered and acquires critical thinking and problem-solving skills in regard to their health care decisions. As a result, individuals are enabled to assume greater responsibility for their health, health care, and general well-being.

The ultimate goal of self-management patient education is to teach individuals to manage their illness and therefore enhance their ability to cope with the challenges of life. With the focus of minimizing disability, suffering, and activity limitation, self-management health education programs have the potential for improving quality of life and reducing health services utilization (Lorig, Mazonson, & Holman, 1993).

Furthermore, as individuals are enabled to self-manage their chronic disease(s), they gain a sense of control and are empowered by their illness, rather than being overwhelmed by it.

Benefits of self-management health education include increased personal control, enhanced patient satisfaction, improved self-concept, and increased self-efficacy (Gibson, 1991). Specifically, arthritis self-management educational programs have been shown to be effective in improving several aspects of the participant's health knowledge, behaviors, and outcomes, that is, activity level, disability, pain and emotional state (Lorig, Lubeck, Kraines, Seleznick, & Holman, 1985). The mechanism which is believed to be responsible for the favorable outcomes of arthritis self-management education programs is believed to be based in self-efficacy theory (Lorig & Gonzalez, 1992). Self-efficacy, which can be defined as one's confidence to perform specific behaviors, is therefore thought to be the primary determinant of health outcomes within these programs. In this sense, self-management education influences health status by increasing self-efficacy, which in turn improves health behaviors, motivation, thinking patterns, and emotional well-being (see Figure 1).

Despite the benefits of self-management educational programs to individuals with chronic health conditions and the health care system in general, not all individuals who are diagnosed with a chronic illness participate in the available programs. Furthermore, while the results of the studies surrounding programs indicate significant benefits to individuals with arthritis (Lorig & Gonzalez, 1992), not all individuals who participate in the programs enjoy favorable outcomes. For example,

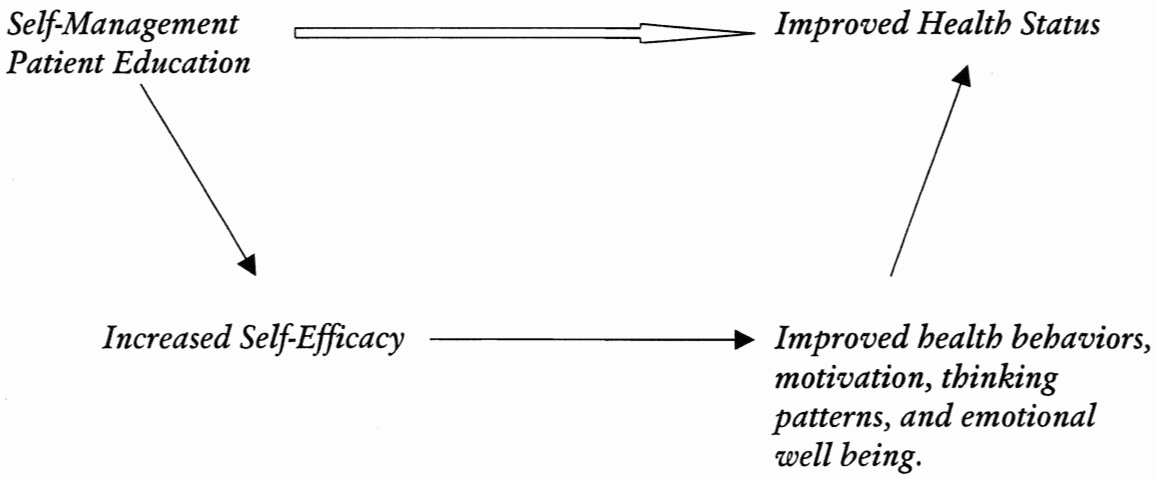

Figure 1. The relationship between self-management health education and health status.

Adapted from Lorig & Gonzalez, (1992).

some participants of arthritis self-management programs respond positively to the program with good health outcomes, whereas others lack favorable outcomes. Similarly, the relationship between the theory upon which self-management health education is based (self-efficacy theory), and course enrollment and health outcomes has not been explored in detail. Considering the many benefits of this form of health education, the lack of participation and inconsistencies within this model leave health educators baffled as to the reason for these discrepancies between the accepted theory and practice.

The intention of this study was to gain a better understanding of the self-management approach of health education and the treatment of chronic arthritis and to address some of the practical problems occurring within self-management health education. Health care professionals and health educators can benefit from knowing:

1. The role of health education and health educators in the treatment of chronic disease.

2. The difference between the compliance and self-management models of health education.

3. The benefits of the self-management approach to health care and health education.

4. The similarities between the self-management approach to health education and the adult education literature.

5. Why some patients choose to participate in health education programs and why others do not.

6. Why some individuals have good outcomes after self-management programs, whereas others do not.

7. The role of self-efficacy in relation to the adoption of self-management behaviors.

8. The characteristics of individuals who would benefit most from the self-management approach to health care and health education.

In this research, the self-management approach to heath education was studied, focusing on both the theoretical and practical limitations as briefly discussed above. This was done by gaining a better understanding of the beliefs of individuals with chronic arthritis who have participated in self-management health education. This research approach was taken as it was believed that participants of an arthritis self-management program would have valuable insights surrounding the issues of self-management health education.

Considering the scope of this topic, a section describing the background of the problem in more detail is included. This section is intended to provide the reader with supplemental information that is critical in understanding the nature of the problem and rationale for the study.

Background of the Problem

Current Demographics

Current demographics indicate a significant trend toward an aging society in North America. One of the reasons for this trend is increased life expectancy. For

example, those who reach age 65 can now expect to live into their 80s (Shirreffs, 1997). As the average age of the population increases, so does the prevalence of chronic disease and therefore the strain on the health care system. It is now estimated that people aged 60 years and older have, on average, 2.2 chronic conditions, and that chronic disease is responsible for almost 70% of health care expenditures (Lorig et al., 1999). Furthermore, Christianson, Taylor & Knutson, (1998) indicate that the average health care costs for individuals with chronic illnesses are three times the costs of care delivered to others. In consideration of the state of our current health care system, effective and efficient treatment for those suffering from chronic conditions must be a focus of health care reform.

Chronic Disease

By definition, chronic disease is "any condition that lasts for a substantial period of time or has sequelae that are debilitating for a long period of time" (Christianson et al.,1998, p. 3). Although this is a broad definition, historically, chronic disease has been defined only in relation to acute disease. For example, if the condition did not fit the acute care paradigm, meaning the patient could be cured with the removal of the disease, it was labeled chronic. Some examples of chronic diseases include: arthritis, diabetes, asthma, chronic obstructive lung disease, and heart disease.

The nature of chronic disease is such that there is no known cure to the illness. Furthermore, the intensity of the disease varies over time, and the multiple consequences of the disease change and interact with one another in different patterns

(Holman & Lorig, 1997a). Unpredictability of symptoms is characteristic of chronic disease and commonly leaves the individual feeling helpless and with the belief that the management of the illness is beyond their ability and control. For example, an individual suffering from rheumatoid arthritis may on a particular day, without warning, have a "flare-up". Their joints may become painful and inflamed, causing the individual to restrict various functional activities. This type of flare- up is common in the case of rheumatoid arthritis, yet without a basic understanding of the consequences of the illness, an individual can experience significant anguish and emotional despair.

Research surrounding the characteristics of chronic disease indicates that there are a number of stages in the disease process. For example, Rolland (1987) indicates that there are three stages of chronic disease and within each phase there are subphases. A more detailed description of the stages is included in Appendix A. Rolland indicates that understanding these phases can provide insight to the course of the disease and the roles of patients and care givers within each phase. For example, Van Eijk & De Hann, (1998) suggest that in the chronicity phase, learning to self-manage the illness is essential. In this sense, the ability to self-manage makes adapting to life with a chronic disease easier and helps to postpone progression in the course of the illness.

In the case of chronic disease(s), the patient is required to be the primary care giver (Clarke et al., 1991). This seems obvious when considering the tasks the patient must perform to deal with the effects of the chronic disease and cope with everyday life. For example, the successful management of chronic disease requires patients to

use medications properly, to change behaviors which can slow disease progression or improve symptoms, to cope with emotional consequences of the illness, and to participate in decisions concerning treatment. Therefore, it is the responsibility of the health care system to adequately prepare patients for the tasks necessary to successfully live with a chronic illness.

The Traditional Medical Model

The traditional medical model was developed at a time when acute diseases were predominant (Holman & Lorig, 1997a). As a result, the traditional medical model, which forms the philosophical foundation of the current health care system, is based on acute disease. In contrast with chronic disease, in acute disease there is commonly a cure. The ultimate goal of treatment within the traditional medical model is aggressive curative treatment of a well-defined disease (Caporael-Katz, 1983). As a result, this model fits well for many acute illnesses, such as infectious diseases, as it is able to identify, describe, and ameliorate the underlying pathology or cause of the illness. This leaves the patient satisfied and grateful for the treatment given and, most important, the ability to return to life as normal.

The traditional medical model is paternalistic in nature. The patient is thought to be inexperienced and a passive recipient to care, while health care providers possess the available knowledge and skill and consequently determine the course of action. In this model, the patient relinquishes their control to the health care providers and as a result can remain dependent upon them. Although this model is most successful in the

case of acute illnesses, such as trauma found in the emergency room, it provides limited effectiveness in the case of chronic conditions. Considering the financial strain that is placed on today's health care system due to chronic illnesses, this model is no longer suitable or sustainable.

Chronic Illness and the Traditional Medical Model

In the case of chronic illnesses such as arthritic conditions, the traditional medical model is insufficient for many reasons. To the dismay of many individuals diagnosed with a chronic condition, the cause of the disease in many cases is uncontrollable degenerative body breakdown where a cure is unavailable and symptoms can only be managed. Unfortunately, the traditional medical model has formed society's beliefs of health and health care, and as a result many individuals who suffer with chronic conditions live with the hope of a cure and in a state of denial, which does not allow for successful living with the disease. As indicated by Christianson et. al. (1998), "it is critical to the success of the health care system to recognize that intensive high technology treatment oriented toward a cure and full restoration of function is usually inappropriate to the needs and problems of the chronically ill" (p. 5). Therefore, it is necessary that the goal of treatment in the case of chronic disease is to learn to live a full and satisfying life while managing the consequences of the disease over time.

The paternalistic, prescriptive philosophy behind the traditional medical model of health care does not promote effective treatment of chronic conditions, as the

philosophical underpinnings of traditional health care are conflicted with the very nature of chronic disease. For example, as the symptoms of chronic disease are unpredictable, individuals suffering from chronic conditions often live with the sense that the disease is out of their control. This feeling of lack of control is further enhanced in the traditional medical model, as the health care practitioner holds all the control. Similarly, the unilateral decision-making power that is characteristic of the traditional medical model results in further dependency on the health care provider, as patients are not enabled to develop critical thinking and problem-solving skills. Thus, treatment of chronic disease within the traditional medical model can provoke feelings of helplessness and dependency that those with chronic disease are inherently prone to, and therefore does not promote independent, healthy living with a chronic disease. For the success and sustainability of the current health care system, in the case of chronic disease, a shift from the traditional medical model is required.

The nature of chronic disease requires a different, more holistic approach to treatment. The individual living with the disease must become experienced with the illness and deeply involved in the care process. Over time, the intensity of the disease varies, and as a result constant observation and management are essential. For example, being able to judge accurately the trend and tempo of the disease and to adjust activities accordingly is necessary (Holman, 1997). Furthermore, adapting one's environment wherever possible, i.e. reducing obstacles and impediments at home and modifying the workplace so as to minimize handicap is important. Therefore, in

chronic disease the patient becomes the principle actor and a crucial evaluator (Holman & Lorig, 1997b).

To effectively treat chronic conditions, a partnership between the individual and the health care provider is essential. The role of the health care provider becomes less authoritative and paternalistic and more focused on reinforcing the individual's role while contributing professional knowledge. From this point of view, individuals with chronic health conditions are given responsibility for their health and well-being and are appropriately prepared for their roles as self-managers. This approach to the treatment of chronic disease equalizes the power dynamic between the individual and the provider and promotes a sense of control and empowerment to the individual.

Health Education and Chronic Disease

Considering the characteristics of chronic disease (i.e., unpredictable symptoms and without cure), patient education plays a crucial role in the treatment of chronic health conditions. Holman & Lorig, (1997b) indicate that the current health care crisis is a result of the disjunction between a health care system created to cure acute disease and the increased incidence of chronic disease that the system confronts. Furthermore, Holman & Lorig, (1997b) advocate that a health care goal is for every patient who suffers from a chronic illness to have opportunities to participate in health education programs specific to managing their chronic illness. Holman & Lorig, add that these educational opportunities would "not only better serve the needs of the individual

patients, but would also contribute meaningfully to the resolution of the health care crisis" (p. 1373).

Individuals diagnosed with a chronic disease must be taught how to care for the disease. For example, patients must be shown how to use medications, to perform and progress therapeutic exercises, and balance rest with activity. In addition, they need to be shown strategies focused on preventing the condition from progressing to further impairment or disability. In this sense, health education can help to empower the individual with the disease in their decision making and to come to terms with their situation-all of which can have a healing effect.

The self-management model of health education enables and empowers patients to take responsibility for their own health and health care and equalizes the power dynamic between the patient and the health care provider. Considering the nature of chronic disease, this form of health education is thought to be more effective in the treatment of chronic conditions than the traditional models of health education. The focus of this project is the self-management approach in the treatment of chronic health problems-specifically chronic arthritis. The remainder of this chapter outlines the questions to be answered and the rationale of the study.

Problem Statement

The benefits of the self-management approach to patient education in the treatment of chronic disease are well-documented (Clark, et al., 1991; Cohen, Van Houten Sauter, De Vellis & McEvoy De Villies, 1986; Goeppinger, Arthur, Baglioni,

Brunk & Brunner, 1989; Goeppinger, Macnee, Anderson, Boutaugh & Stewart, 1995; Lorig & Gonzalez, 1992; Lorig, Laurin & Holman, 1984; Lorig et al., 1999; Lorig et al., 1996; Mazzuca et al., 1997; Mazzuca, Brandt, Katz, Hanna & Melfi, 1999). Despite the significant benefits of the self-management approach, limitations of this form of health education do exist. First, not all individuals living with chronic disease(s) are interested in helping themselves or changing their health status. For example, Williams et al. (1998) indicated that individuals who had very little interest in reading about improving their health were less motivated and therefore less likely to attend health promotion and education programs. This suggests that participants in health education programs may already be a "health conscious" group, and that these types of programs may not attract those who might benefit the most.

Considering the number of individuals with chronic health problems, course enrollment is low and attendance is poor in self-management health education programs. It is unclear whether the lack of participation within self-management programs is due to low levels of interest among patients and poor marketing and advertising strategies, or due to patient expectations that are built from the longstanding compliance model of health. For example, patients may have been conditioned to remain passive and dependent in relation to their health and health care, and therefore interpret the concept of self-management and health education as of low importance.

Another limitation within self-management health education programs is that not all participants are guaranteed favorable results. Although the literature shows

that most participants benefit from these programs and that the benefits are statistically significant, not all participants have positive outcomes (Lorig et al., 1984). Although these limitations are expected with any form of education (i.e., not all students are interested in learning mathematics or have positive outcomes when learning to play tennis) they are still areas of concern.

A third issue within the self-management literature surrounds the theory that supports the curriculum of self-management programs. The role of self-efficacy in mediating health status in arthritis self-management programs has gained acceptance in the literature (Lorig et al.1996). As a result, most self-management programs base curriculum and teaching methods around self-efficacy theory. Although efficacy-enhancing strategies have been reported to significantly increase health outcomes of arthritis self-management programs (Lorig & Gonzalez, 1992), the role of self-efficacy status in relation to course enrollment and outcomes is unclear.

By investigating some of these limitations of an arthritis self-management program, greater understanding in the areas of self-management patient education participation, curriculum, teaching methods, and patient outcomes will develop. As a result, improvements to self-management health education interventions may follow.

Purpose

The purpose of this research project was to investigate the self-management approach to health and health education. The focus of this investigation was to develop a better understanding of the characteristics, experiences and beliefs of

individuals who participated in an arthritis self-management program. Specific questions to be answered as a result of the research were:

- What is the difference between the compliance and the self-management models of health education?
- What is the relationship between self-efficacy theory and the self-management model?
- What is the relationship between the self-management model and the adult education literature and Friere's educational philosophy?
- What are the traits of individuals with chronic arthritis who choose to participate in self-management programs?
- What are the beliefs of individuals in the Arthritis Self-Management Program (ASMP) who chose to participate in an arthritis self-management program in regards to topics such as chronic disease, health care, health education, the compliance approach to health education, and the self-management approach to health education?
- Are the self-management course outcomes generally better for those with high self-efficacy to self-manage in comparison to those with low self-efficacy to self-manage?
- Which learning strategies were the most and least helpful to participants with low and high self-efficacy in learning to self-manage?
- Is the self-management approach to health education better suited to individuals with high self-efficacy to self-manage?

- What are determinants of adoption of the self-management approach to treatment of chronic disease?

Rationale

The current health care system is presently under significant reform, with the ultimate goal to improve both health care efficiency and effectiveness. One focal area of health care reform is home care and patient self-care or self-management. As health care dollars are being cut or reallocated to ambulatory care, the demand for health education mounts. For example, as the average hospital stay for patients recovering from a total hip joint replacement surgery is reduced, patients are being sent home in a state of increased convalescence and are required to manage their own health needs. Thus, for health care reform of this type to be successful, individuals must be educated in strategies of how to manage their recovery independently. To aid in this process, educational programs with the focus of patient self-management must be in place before aggressive discharges from hospitals occur. Furthermore, for these educational programs to produce favorable results, research is needed to indicate how to make self-management educational programs effective and efficient for the patients for whom they were designed.

The shift from more traditional models of health and health care to more holistic models of health will help the health care system better meet the needs of individuals with chronic illnesses. The self-management approach to health care and health education can improve quality of life, enhance satisfaction with patient care by

both the providers and patients, and result in better health outcomes, all while decreasing health care costs. Considering the demographic changes in current society, such as increased life expectancy and increased incidence of chronic disease, the self-management treatment approach is essential for the sustainability of the health care system. Researching this approach to health care and health education in the case of chronic illness may heighten professional and public awareness of the alternative to the more traditional approaches to health care. Furthermore, research in this area of health education may assist health care professionals and health educators in participating in and advocating for self-management health education as an important adjunct to the treatment of chronic health conditions.

The shift to the self-management model from the traditional medical model in the case of chronic illness will occur slowly over time and requires facilitation by health care professionals and health educators. Gaining further understanding from those who are successfully self-managing a chronic disease may help health educators in designing programs that will assist others who wish to make the transition from compliance to self-management.

Considering the number of individuals diagnosed with chronic disease, the enrollment for health education programs focused on the management of chronic conditions is low. Gaining deeper understanding as to the reasons for low enrollment from those who do participate in programs may help health educators and health care professionals in promoting the programs more effectively. Furthermore, the research may suggest ways to modify programs in a way that may pique the interest of

individuals who in the past have not been interested in helping themselves and participating in programs.

The role of self-efficacy in the self-management of chronic conditions is well established. Numerous studies have indicated that increased levels of self-efficacy result in increased self-management behaviors and health outcomes (Clark et al., 1991; Lorig & Gonzalez, 1992). Surprisingly, when the literature was reviewed, no studies were found that described the participants' beliefs around the concept of self-management in relation to their outcomes or levels of self-efficacy. Gaining a better understanding about the beliefs of individuals in self-management programs may help educators to better comprehend the connection between self-efficacy and self-management. This enhanced understanding may in turn help educators improve upon current curriculum, enhance participation within the programs, and raise health outcomes.

Definition of Terms

Chronic Disease and Illness

In this study chronic illness is defined as any illness that has remained or is expected to remain longer than 3 months in duration. In the literature, the terms chronic disease and chronic illness have similar meanings, and as such will be used interchangeably in this paper. Furthermore, to remain consistent with the language of the study participants, in this study the terms chronic disease and chronic illness are used synonymously.

Chronic diseases are characteristically without a known cure. Chronic diseases can vary greatly with regard to onset (acute or slow), course (progressive, remissions, constant), and consequences (Van Eijk & De Hann, 1998). Chronic illnesses all have one thing in common: the prolonged course of the disease. Common types of chronic diseases include: arthritis, diabetes, stroke, hypertension, chronic obstructive lung disease (COPD), and asthma.

Arthritis

In this study, any arthritic condition is referred to as arthritis. Common arthritic conditions include: osteoarthritis, rheumatoid arthritis, psoriatic arthritis, systemic lupus, fibromyalgia, gout, and ankylosing spondylitis. Literature in the field of rheumatology indicates that there are over 150 different types of arthritis (Lorig & Fries, 2000).

All types of arthritis are characterized by inflammation of body tissue such as joint, muscle, tendon, bursa, ligament, fascia, and/or viscera. Specific types of arthritis affect different body tissue and result in different symptomology. For example, rheumatoid arthritis is a result of inflammation of all aspects of the joint (synovium, ligaments, cartilage, bone, joint capsule), whereas osteoarthritis affects only bone and cartilage. Common features and symptoms across all types of arthritis include: inflammation characterized by redness, swelling and pain, point tenderness, fatigue, stiffness, joint deformity, muscle aches, activity limitation, and sleep disturbances. Some common goals in the treatment of arthritis include: to improve physical

function; to minimize pain, disability, and deformity; and to diminish the social and psychological dysfunction that can accompany arthritis.

Health Education

In this study, health education refers to any form of teaching and learning pertaining to health and health care.

Patient Education

In this study, patient education is a form of health education. Patient education is any form of teaching and learning which occurs between health care professionals or health educators and patients. The term patient refers to the consumer of health care. In the field of health care, the term client is often substituted for patient to imply a less dependent role. However, within this study the term patient is used to remain consistent with the language of the study's participants, but in no way is intended to project an image of a passive, dependent role upon the patient.

Compliance Model

In this study, the compliance model is a philosophical model of health care and health education. Compliance-based health care and health education are oriented in the traditional medical model. In this model, health care professionals are the prime caregivers and decision-makers for patients, because of their medical expertise. There is an unspoken hierarchy of authority in which the health care provider holds all the

power. Patients are expected to perform the health care behaviors recommended by their health care professional and are conditioned to be passive and dependent in this relationship. Assumptions of this model include that health care professionals are altruistic and that patients benefit from compliance (Roter, 1987).

Self-Management Model

Self-management is a philosophical model of health care and health education. In the self-management model, patients assume greater responsibility for their own health and health care. Self-management not only enables individuals to reduce their dependence on the formal health care system, thus potentially reducing health care costs, but also offers a new sense of self-efficacy and satisfaction at having managed problems independently.

The self-management model enables patients to gain control over identifying their needs, and planning, implementing, and evaluating strategies to meet their needs. Self-management programs focus on individuals becoming an active partner with health care providers. In this model, health care providers view patients holistically and assume a facilitation role. Furthermore, in self-management, patients are not only given information but are guided in applying knowledge gained, therefore empowering and enabling them to make informed decisions about their health. Chronic disease self-management programs are designed to provide individuals with the skills needed to carry on physically active and emotionally satisfying lives in the face of chronic illness.

Health Care Practitioner

In this study, the term health care practitioner refers to all categories of caregivers in the health care system and is synonymous with the terms health care professional and health care provider. This includes physicians, nurses, health educators, and allied health care professionals such as physiotherapists, occupational therapists, speech and language pathologists, dietitians, podiatrists, psychologists, audiologists, respiratory therapists, and radiation therapists.

Self-Efficacy

Self-efficacy is a theoretical construct which is part of social learning theory. In this study, self-efficacy refers to the belief in one's own capacity to perform specific behaviors needed to control events affecting one's welfare. The concept of self-efficacy plays an important role in the initiation and maintenance of behavior change and therefore is of particular relevance in the field of health education (Bandura, 1986).

CHAPTER TWO: REVIEW OF THE LITERATURE

This chapter serves to outline the related literature that is critical to understanding the theoretical basis of this study. The literature reviewed addresses topics such as health education, the compliance model of health education, and the self-management model of health education. To gain further understanding of the theory and introduce the program used to investigate the principles of self-management, an example of the self-management approach is described and supporting literature is discussed. Assumptions of health education that are apparent in the literature are outlined and are used to introduce the concept of self-efficacy and the relationship between self-efficacy theory and health education. Self-efficacy, another theoretical underpinning of the study, is then described in detail and is related back to health education theory using chronic illness as an example. Finally, a review of the literature in the field of adult education and Freire's educational philosophy are included, and the connection to the self-management model is revealed.

Health Education

Health education is an important component of medical care and is essential for the success of today's health care system. Specifically, Rankin and Stallings (1996) define patient education as "the process of influencing patient behavior, and producing changes in knowledge, attitudes, and skills required to maintain and improve health" (p. 300). Health education programs can be valuable in achieving behavioral,

physiological, and psychological goals, which in turn can lead to lower utilization of health care services, a higher quality of life, and improved functional ability (Williams et al., 1998). Furthermore, education enables patients to make intelligent, informed decisions regarding their health, provides continuity of care from home to hospital and in returning to home, and helps to decrease spiraling health care costs (De Amicis, 1997). Redman (1997) and Rankin and Stallings (1996), advocate patient education to empower informed decision making, influence behavior, alter attitudes, and reduce dependency on the health care system. Although there are many goals of health education, three most commonly cited in the literature include: promotion of health and illness prevention, restoration of health when there is illness, and maintenance of health while coping with chronic long-term conditions. Educational programs for patients with chronic long-term conditions such as arthritis are generally viewed as complements to, and not replacements for, professional health care.

In reviewing the health education literature, a variety of pedagogical approaches including the compliance model, the preventative model, the radical political model, and the self-management model are discussed. Considering the characteristics of chronic disease, the self-empowerment model or self-management model seem most appropriate when educating those with chronic conditions. These models have the basic philosophy that suggests empowering the individual to facilitate choices through informed consent (De Amicis, 1997). In both of these models, deliberate efforts to learn involve action, reflection, and self-monitoring. In this sense, these models of health education are concerned not only with attaining knowledge, but in helping

clients to develop their skills as critical thinkers and independent decision makers. Furthermore, De Amicis indicates that the concept of self-efficacy, which she indicates to be "the belief that it is possible to be in charge of one's life" (p. 13), is an important component of these approaches to health education.

The Compliance Model of Health Education

Traditionally, patient education has occurred within a compliance model of medicine. The compliance model can be described as "the correct and appropriate performance of recommended health care behaviors" (Bartholomew et al., 1991, p. 431). In this sense, the goal of teaching patients is to have them comply with medically prescribed treatment regimes. Roter (1987) suggests that the compliance model is characterized by authoritative guidance, as there is high control and responsibility on the part of the health care professional (and low patient control and responsibility). As a result, patients relinquish control of their health decisions to a health care professional whom they see as having expert knowledge and decision-making power. In the compliance model of health education, patients are conditioned to be passive and dependent, and the education regarding their health care becomes a one-way transmission of knowledge (Anderson, Funnell, Barr, Dedrick & Davis, 1991). This model of patient education commonly results in feelings of helplessness and lack of control over one's health and health care.

Authoritative guidance that is characteristic of the compliance model is consistent with traditional medical paternalism; the provider is the dominant,

authoritarian figure in the relationship, assuming both the responsibility and the right to make medical decisions in the best interest of the patient (Roter, 1987). Thus, in this model, the relationship between the health care professional and the patient is such that there is an asymmetrical distribution of power, one that could be considered like that of parent and child.

For several reasons, the traditional passive, dependent role required of the patient in the compliance model is not consistent with the demands of managing chronic disease. First, Tones, Tilford, and Keeley Robinson, (1990) indicate that the health care professionals' perceptions of patient needs is a poor match with the needs identified by the patients. This may be because the provider's personal values and beliefs cloud their perceptions of the individual in need of care. In this case, when patient individuality is not considered and needs are not met, those with chronic conditions may not be able to achieve their full health potential, and as a result, suffering with the chronic illness ensues.

Second, the obvious imbalance of power between client and provider in the compliance model results in the assumptions of client trust and provider altruism (Roter, 1987). Thus, the potential for poor patient care and health outcomes is substantial, as patient needs are not met. Furthermore, the relationship between patients and providers begins on such significant unequal footing that few patients have an opportunity to effectively develop a more egalitarian relationship. In many instances, lacking prior experience, some patient's expectations regarding modes of conduct within the health care setting are likely to be quite narrow. Within this

context, the thought of independent or even shared decision making by the patient may be quite foreign. Therefore patients may adapt to the traditional models of medicine by default, not fully aware of any alternative or without the ability to negotiate a more active stance. Considering the value placed on free choice in today's society, this form of relationship seems to be out of place and out of date.

In the compliance model, the medical perspective precludes the patient's perspective, and as a result, the individuality of the patient is not taken into consideration. Furthermore, little thought is given to the psychological processes involved in the patient's decision making, such as their beliefs about their illness, their coping mechanisms, and their outcome and efficacy expectations to perform prescribed "therapeutic" tasks. Despite this lack of involvement in the decision-making process and low regard for the patient as an individual, patients are held responsible for the results of their health behaviors, which in many cases may be poor. This unbalanced power distribution and responsibility for outcomes further promotes feelings of lack of control and helplessness, and ultimately inhibits empowerment of the patient.

Another limitation of the compliance model of health education is that compliance rates of health behaviors were reported to be as low as 50% and they decreased over time (Roberson, 1992). Furthermore, it is uncertain that even high levels of compliance are linked to improved health status (Levanthal & Cameron, 1987). This result may be due to the fact that patients who were not involved in the decision making and other health care processes may be just "going through the motions", as they may not have wholeheartedly bought into the prescribed treatment.

As a result, the traditional compliance approach fails to reach the goal of maintaining long-term changes in behavior-an outcome that is crucial to the successful management of chronic disease.

Considering the social fabric of today's society, the passive dependent role of patients that is found in the traditional medical model and the compliance model of health education is no longer acceptable. Patients require a more active role in the management of their health and health care and deserve the opportunity to make informed decisions regarding their health. Furthermore, patient dependency on the health care system is no longer sustainable considering the economic strain that high patient reliance puts on the health care system.

The Self-Management Model of Health Education

One form of patient education well suited to the treatment of individuals with chronic conditions is the self-management model (Lorig & Gonzalez, 1992). The self-management approach to patient education encourages individuals to take responsibility for their own health and health care. In this model, individuals are taught the life skills necessary to successfully live with the consequences of the chronic disease. As a result, the individual living with the chronic disease becomes experienced with the illness and is enabled and empowered to become deeply involved in the care process.

In the self-management model, the role of the health care professional is more of facilitator, consultant, joint problem solver, coach, or counselor. The self-

management model is characterized by active participation, and as such there is a high level of control and responsibility for both the health care professional and the patient. Furthermore, health care professionals take the patient's individuality into consideration and guide them in their decision making in light of personal values and relevance for the patient.

Self-management includes all tasks required to handle the clinical aspects of the disease away from the hospital or health care practitioner, as well as psychosocial coping strategies (Clarke, 1991). Furthermore, Clarke indicate that successful self-management of a chronic illness requires that individuals master three separate but related categories of activities. First, they must be adequately knowledgeable about their condition and the appropriate treatment to make informed decisions about their care. Second, they must perform activities aimed at management of the condition. Third, they must apply the skills necessary for maintaining adequate psychosocial functioning, that is manage the feelings associated with a worsening arthritic condition. Similarly, Corbin and Strauss (1988) indicate that self-management strategies seek to improve health status and lessen health care utilization by teaching individuals how to self-mange a chronic disease through three types of work:

> 1) The work to care for the disease, including taking medication, maintaining a special diet, and exercising; 2) The work to maintain a normal life, including activities of daily living, social outlets, and hobbies; and 3) The emotional work required in order for an individual to deal with feelings like frustration, depression and anger, as well as adjustment to life altered by the disease. (p. 10).

Together all of these behaviors are aimed at reducing the impact of a chronic disease on daily life.

In a review of the self-management literature, Clark et al. (1991) reported the common self-management tasks and themes for a variety of chronic diseases. For example, the most common tasks for self-managing chronic arthritis included (Clark et al., 1991):

1. Using medicine properly.
2. Managing acute episodes and emergencies.
3. Maintaining nutrition and diet.
4. Maintaining adequate exercise and activity.
5. Giving up smoking.
6. Using relaxation and stress-reducing techniques.
7. Seeking information and using community services.
8. Adapting to work.
9. Managing relations with significant others.
10. Managing emotions and psychological responses to illness.

Benefits to the self-management approach of health education include increased patient satisfaction, enhanced self-concept, a heightened sense of personal control, and increased self-efficacy (Gibson, 1991). Furthermore, studies surrounding the efficiency and effectiveness of self-management patient education programs suggest significant reductions in health care utilization with resultant cost savings (Lorig et al., 1993). Self-management patient education is gaining acceptance as an effective and efficient

adjunct to treatment of those with chronic conditions. An excellent example of self-management patient education theory in practice is the Arthritis Self-Management Program.

The Arthritis Self-Management Program

The Arthritis Self-Management Program (referred to as ASMP herein) was initially developed in 1978 as part of the arthritis education research project at the Stanford Arthritis Center at Stanford University in California. The purpose of this research was to develop and evaluate a low-cost, community-based patient education program for people with arthritis. The goal of the project was that the program would improve health status, defined as lowering pain, disability, and depression and would reduce health care utilization (Lorig, 1986). The ASMP continues to be used as a template for much of health education and arthritis care research. As reported by Lorig in 1995, more than 2,500 people have participated in research studies using the ASMP as an example of self-management health education.

The Arthritis Self-Management Program was developed with a focus on building knowledge of the disease and promoting the skills necessary to manage the problems caused by arthritis. The philosophy of the course is to present a large number of self-management skills, offer practice of the skills, and assist participants in choosing techniques that work best for them as individuals. Therefore, the program assists individuals with arthritis in taking a more active role in their arthritis care and health care in general.

The ASMP seeks to help people with arthritis change their activities and abilities, decrease their pain, and most important, develop more confidence in themselves as caretakers for their bodies (Lorig & Fries, 2000). As described in the ASMP leader's manual (Lorig, 1995), three main concepts are emphasized in the course:

1. Each person with arthritis is different. No one treatment is right for everyone.

2. There are a number of things people can do to feel better. These things will not cure most kinds of arthritis, but they will help to relive pain, maintain or increase mobility, and prevent deformity.

3. With knowledge, each individual is the best judge of which self-management techniques are best for him or her.

The ASMP is a 12-hour program, taught at community sites over 6 weeks. The program is taught using a standardized protocol, yet within the teaching protocol the program is taught in a nonprescriptive manner, meaning that the participants are taught problem solving and critical thinking when faced with problems of the illness. For example, common learning activities within each session of the course include contracting, goal setting, group discussion, and problem solving with the instructor and fellow participants. In this sense, the program curriculum is both content and process oriented. Topics covered in the ASMP include the uses and effects of medications, exercise, pain management, nutrition, patient-physician communications, and solutions to disease-related problems (Lorig & Holman, 1993).

The instructors of the ASMP are volunteers and are primarily lay persons who have arthritis and have been through 15 to 18 hours of training. Lorig (1986) indicates the reasons for the use of volunteer lay instructors include lack of health care professionals who have the knowledge, skill, and desire to handle the massive numbers of participants, in addition to the fact that the time of health care professionals would be costly. Furthermore, there is good evidence that some of the strongest patient educators in the most successful programs have been lay people. For example, Lorig (1986) compared lay-taught and professional-taught arthritis self-management programs and found that lay leaders can teach an arthritis self-management program from a standardized protocol and achieve similar outcomes to those achieved by health care professionals using the same standardized protocol.

Reported benefits of the ASMP include: patients report fewer symptoms, less emotional distress, increased activity levels, and independent living, decreased health care costs, and increased levels of personal satisfaction (Holman & Lorig 1997b). These benefits were maintained at 4, 8, and 20 months and 4 years after completion of the program as participants continued to show significant improvements in health outcomes (Lorig & Gonzalez, 1992). In a similar study, Lorig (1993) reported the effects of the ASMP 4 years after the program was complete and found reductions in pain and visits to physicians when comparison groups did not. From this study, Lorig, et.al (1993) suggest that "estimated cost savings are significant as a result of the program" (p. 439). Overall, the results of the research done on the ASMP have been so successful that the course has been disseminated in the United States by the American

Arthritis Foundation, in Australia by the Australian Arthritis Society, and in Canada by the Canadian Arthritis Society. As discussed in the methods section of this paper, the ASMP was used as an example of the self-management health education phenomenon in this research study.

Assumptions of Health Education

Traditionally, health education research and practice have relied on some significant assumptions that in recent years have been challenged. A main assumption underlying in health education research is that an increase in health-related knowledge results in improved health behaviors, which in turn leads to improved health status (Lorig, 1985). This assumption is so widely held that few health education studies correlate changes in health knowledge and behaviors with changes in health status. Therefore, it is assumed that any changes in health status can be attributed to changes in knowledge and behavior.

Recent research in the field of health education is challenging this assumption as it indicates that there is no correlation between improved health behaviors and outcomes. For example, Lorig (1984) found that the Arthritis Self Management Program (ASMP) resulted in improved health behaviors and health status; however no association was found between the two. That is, the people who had successfully changed their health behaviors were not necessarily those who had improved health outcomes, such as less pain or depression. The results of these studies have challenged

the traditional assumption inherent in health education research that increases in knowledge and improved health behavior lead to improved health outcomes.

To investigate the missing "link" between changes in health behaviors and outcomes, researchers working with the ASMP conducted a retrospective hypothesis-generating study (Lenker, Lorig & Gallagher, 1984). Results of this study indicated that participant's beliefs about their arthritis had a direct effect on their health outcomes. For example, individuals with good health outcomes felt more in control of their symptoms, whereas individuals with poor outcomes felt there was nothing that could be done about arthritis. These findings led researchers to investigate the relationship between self-management health education and self-efficacy theory.

According to Bandura (1977), one's self-efficacy or confidence in his or her ability to accomplish a specific behavior is a good predicator of actual future behavior. Thus, if one were confident that he or she could exert some control over their pain, the pain would probably be less. Lorig and Gonzalez (1992) found that favorable health outcomes were found to correlate much more strongly with the patient's baseline levels of perceived self-efficacy to cope with the different consequences of chronic arthritis and with the growth of that perceived self-efficacy during the arthritis self-management program. It is now widely accepted in the literature that self-management health education results in enhanced self-efficacy to manage a chronic illness, which in turn leads to improved health outcomes (see Figure 1, Chapter One). As a result, self-efficacy theory is key to understanding the relationship between health

knowledge, health behaviors, and health outcomes in self-management health education.

Self-Efficacy Theory

Self-efficacy is a construct of social learning theory and is of particular relevance within the study of health education, as it plays a significant role in the initiation and maintenance of behavior change (Stretcher, McEvoy-De Vellis, Becker & Rosenstock , 1986). In reviewing the literature, enhanced self-efficacy leads to improved health behavior, motivation, thinking patterns, and emotional well-being (Bandura, 1986). For example, in a study of individuals suffering from chronic arthritic conditions, the higher the perceived coping efficacy, the less pain, depression, stress, and disability experienced, and the greater the prevention of future joint impairment (Stretcher et al., 1986).

Self-efficacy is defined as one's confidence or belief that he or she can achieve a specific behavior or cognitive state (Lorig & Gonzalez, 1992). Self-efficacy theory states that a person will act to change a behavior if two conditions are met: a) they see that a certain behavior will probably lead to desirable results (outcome expectations), and b) they are reasonably sure they can successfully engage in the behavior (self-efficacy expectations). This suggests that individuals suffering from chronic disease(s) will participate in self-management behaviors if they believe the behaviors only will produce desired outcomes and if they have a high level of confidence in their ability to perform the new behaviors and their control over symptoms in general. For example,

an individual with osteoarthritis of the knee may believe in the benefits of increasing quadriceps strength to prevent further impairment, yet may not participate in a strengthening program due to lack of confidence in their ability to perform strengthening exercises. Similarly, Bandura (1997) suggests that some individuals with extensive physical impairments lead active, productive lives despite the constraints of the illness, whereas others with minimal impairment restrict their activities, and generally give up on life, becoming a prisoner to their illness. Furthermore, Bandura (1997) indicates that in the case of chronic arthritis, functional limitations may be governed more by beliefs of capability than by degree of actual physical impairment. Considering the link between self-efficacy theory and health behaviors and outcomes, understanding of the principles of outcome and efficacy expectations are critical to the success of health education programs.

Self-efficacy theory states that knowledge of one's efficacy is derived from four sources of information: performance attainment, vicarious experiences, verbal persuasion, and physiological states (Bandura, 1977). As performance attainment is based on actual skill mastery, it is the most influential source of self-efficacy beliefs (Bandura, 1986). For example, an individual suffering from chronic arthritis who has been successful in the past at self-management of health related issues may have high self-efficacy to manage their arthritic condition. In this example, successful past performance builds present efficacy.

Self-efficacy theory, in contrast to most of the other models of health behavior that are only concerned with prediction of health habits, also offers guidance on how

to change health behaviors. Bandura (1986) states that one's self-efficacy beliefs can be enhanced through performance mastery, modeling, reinterpretation of symptoms, and social persuasion. The operative nature of self-efficacy theory enables health educators to use theoretical principles to devise programs that suit the needs of individual participants, therefore enhancing efficacy and in turn, improving health outcomes. For example, incorporating strategies such as peer modeling, vicarious experience, and verbal persuasion into health education programs has been shown to enhance health outcomes (Lorig & Gonzalez, 1992).

According to self-efficacy theory, the strength of an individual's belief in their capacity to do a specific task or achieve a certain result is a good predictor of motivation, and behavior (Bandura, 1986). Considering the role of self-efficacy in mediating health behaviors, motivation and ultimately outcomes, it is important to understand the concepts and principles of self-efficacy theory in relation to health education theory and practice.

Self-Management of Chronic Arthritis and Self-Efficacy Theory

Successful management of chronic disease is not simply a matter of knowing what to do; rather it requires a capability to organize and integrate cognitive, social, and behavioral skills to meet a variety of purposes (Bandura, 1986). Furthermore, coping with chronic disease requires not only knowledge and skills, but also a belief in one's ability to use those skills in realistic contexts and a belief that the use of the skills will produce desired outcomes.

In the case of chronic disease, the ultimate goal of treatment is to retard the progression of impairment to disability and to improve the quality of life. Therefore, the treatment of chronic disease must focus on self-management of the physical condition over the lifetime, rather than on a cure. Unfortunately, rather than receiving enabling guidance, most people suffering from chronic disease(s) are heavily medicated or simply prescribed health guidelines that, all too often, they fail to put into practice. As described by Bandura (1986) an individual's problems of adherence stem more from disbelief in their efficacy to manage the disease than from physical debility, pain, or disease activity.

The goal of using efficacy-enhancing strategies to teach self-management skills is to empower clients to exercise increased control over their own health. Bandura (1997) indicates, "belief that one can exercise some control over pain and one's physical functioning is also accompanied by fewer pain behaviors, less mood disturbances, better psychological well being and more active involvement in everyday activities" (p. 269). As the daily symptoms of chronic illness are unpredictable in nature, increased confidence to manage the consequences of the disease as they develop returns the power to the patient rather than to the health care professional or to the disease itself.

In reviewing the literature, incorporating efficacy-enhancing strategies into self-management health education curriculum has been shown to improve health outcomes. Lorig & Gonzalez (1992) showed that, when comparing the original ASMP with a modified ASMP program that focused on more efficacy-enhancing strategies, the modified ASMP program produced better outcomes than the original program. As

a result, many efficacy-enhancing strategies are incorporated into the course and function as the template for the learning processes of the course. The following is a brief summary of the specific efficacy-enhancing strategies that are used in the ASMP (Lorig, 1995):

1. Contracting: As one of the best ways of gaining confidence is through mastering something new, weekly contracting assists in the process. In the ASMP, contracts are shared so that open dialogue and feedback are available.

2. Feedback: This gives participants information about their performance and acts as a motivating force for them to try to do more and adopt different behaviors.

3. Modeling: People learn and try harder when they are motivated by people whom they perceive to be like themselves. Program participants serve as models for each other; as well, lay leaders who have arthritis are excellent models for participants.

4. Reinterpretation of Symptoms and Changing Beliefs: People generally act based on beliefs. If these beliefs are wrong, inappropriate behavior may result. Throughout the course, the focus on information sharing, group discussion, and development of new skills such as self-talk emphasizes changes in beliefs that are unfounded.

5. Persuasion: Persuasion is another way to build confidence and enhance self-efficacy and is used as part of the program process in ways such as group problem solving, discussion, and contracting.

The results of the research compiled on the ASMP indicate that self-efficacy is a significant mediator in enhancing health outcomes. It is evident from these studies

that enhancing self-efficacy is an important part of the health educator's approach in order to reinforce positive self-concept, behavior change, coping efforts, and health outcomes.

Adult Education, Self-Directed Learning, and the Self-Management Model

Theories of health care practice and adult education have much in common. For example, most of what occurs within the field of health care is an educational process between the health care professional and the patient. Furthermore, many characteristics of the relationship between patient and health care provider mirror that of teacher and learner within an education model. In this sense, much can be learned from adult teaching and learning principles and applied to the health care system.

The parallel between health care and adult education is even more obvious when considering the traditional and self-management models of health care. For instance, the traditional medical model is mirrored with the more traditional models of education where the teacher is an authoritative figure who decides for the students what should be learned and how to go about the learning. In this relationship, the student is expected to mechanically memorize and repeat what is taught without understanding the true significance of the learning. As a result, students remain as passive spectators in the teaching and learning process and do not develop critical thinking and problem-solving skills. From this example, it is apparent that the traditional models of education are based on a similar philosophy as the traditional medical model of health care and health education such as the compliance model.

The self-management model of health education is mirrored in much of adult education theory. The following literature review will outline in more detail the similarities between adult education theory, including the concept of self-directed learning, and the self-management model. As there are numerous philosophies surrounding adult education and self-directed learning, only those that pertain most closely to the self-management model of health care will be discussed. Furthermore, as this topic is large and complex, the discussion will focus around the following headings that were adapted from a variety of adult education theorists (Brookfield, 1986,1995; Caffarella, 1994; Cranton, 1989, 1992; Galbraith, 1991; Knowles, 1980, 1984):

1. The learner is self-directing.
2. The learner has experience.
3. The learning must be relevant.
4. The educator is secondly a content resource.
5. There should be mutual planning of the program.
6. The educator has the responsibility to encourage self-direction.
7. The learner must be ready to learn.
8. The learning climate must be carefully constructed.

Each of the topics will be discussed using appropriate adult education authors. Furthermore, examples of the relationship between adult education and the self-management model of health care will be provided.

1. The learner is self-directing.

Much of the adult education literature describes the adult as a self-directed learner. In this sense, the adult knows what he or she wants to learn and has input into that learning. The adult educator's role in self-directed learning becomes more of a facilitator, rather than a "delivery system" of knowledge. In addition, the educator promotes a sense of the learner's ownership and responsibility for the learning.

Knowles (1984) refers to the concept of self-direction, as one of the adult learner's deepest needs. Furthermore, Knowles (1980) states that it is a normal aspect of the process of maturation for a person to move from dependency toward increasing self-directedness. Educators who favor this pedagogical approach believe that self-directed learning has numerous benefits over other educational approaches. First, this type of educational format enables the learner to have increased control over the learning, both in their personal style and the learning process itself. In addition, self-directed learning provides the learner with the time and opportunity to study in an area of personal interest, to structure the learning task to suit individualized needs, and to incorporate what is learned into their individual lives. Furthermore, Knowles (1984) indicates that individuals who take initiative in educational activities seem to learn more and learn things better than those who remain passive.

In the self-management model of health care, patients are no longer required to be passive recipients of care. Rather, patients assume increased responsibility for their health and health care and develop their skills as problem solvers and critical thinkers. This model enables patients to gain control by identifying their needs and planning,

implementing, and evaluating strategies to meet their needs. In this sense, patients who are self-managers are also participating in self-directed learning.

Although adults have a deep psychological need to be self-directed, they may be dependent in particular and temporary circumstances (Knowles, 1980). For example, adult learners are prone to be dependent learners when a) they are in new unfamiliar situations where they have no experience with the subject area; b) they have low self-esteem, related to their personal lives or to the instructional situation; or c) they have never experienced self-directed learning (Cranton, 1989).

It is evident from the adult education theory of self-direction that learners who are not comfortable with the self-directed approach to learning may remain dependent on instructors for their learning. In consideration of the self-management model of health care and health education, the same may be true of individuals who are uncomfortable with the concept of self-management. For example, if the individual does not have any experience in self-management tasks or has low self-esteem, they may be less likely to participate in the self-management approach. Considering the role that self-efficacy theory plays in self-management health education as discussed by Lorig & Gonzalez (1992) and Bandura (1986), strategies that enhance efficacy and promote self-management behaviors may also promote self-directed learning.

Cranton (1992) indicates that self-direction is not a characteristic of adults, but a way of learning or process, an outcome of learning, and a goal of adult education. Furthermore, individuals move from dependence to self-direction at varying rates. In this sense, the adult learner can best learn to be independent by evolving out of

dependence. Therefore, it is the role of the instructor of adult learners to nurture this movement (Knowles, 1980).

Caffarella (1994) indicates that adults learn both in independent, self-reliant modes and in interdependent, connected and collaborative ways. As such, in adult education the instructor becomes a facilitator, guide, mentor, resource person, and coach and helps the learner to develop the skills necessary to be self-directed. The skills required to be independent in decision making and responsible for behavior are learned through modeling, practice, and reinforcement. The educator in this way does not relinquish responsibility, but challenges each learner to grow and change in behavior, cognition, and/or function. Considering, that the characteristics of self-directed learning are similar to the self-management model, it may be that self-management is a process which individuals with chronic conditions must evolve into with the guidance and support of a health care professional or health educator. As such, the stages of chronic disease presented in the introductory section and Appendix A of this paper must be taken into consideration. For example, in the prediagnostic and the diagnostic stages of chronic disease, there may be significant dependence on the health care provider, whereas in later stages, such as the establishment phase, the patient is less dependent.

The definition of self-directed learning is subject to interpretation, and within the field of adult education there is much controversy as to its meaning. Much of the literature that has been outlined in this chapter refers to self-directed learning that is interdependent and interactive. Self-directed learning that is independent to an extreme and in isolation of interpersonal dialogue assumes a power reversal in direct

opposition to the traditional compliance model. For example, Cranton (1992) cautions that a risk of a purely self-directed approach is that the individual may not be aware and/or insightful into his/her current situation, possibilities, and potential. In the case of this extreme independent, self-directed approach, the patient becomes dominant with full responsibility for and control over all decisions about his or her own care. Health care providers in this model simply fulfill a technical consultative function. This is an example of self-management to the opposite extreme and has significant limitations. First, the prospect of making important therapeutic decisions without guidance and support can be overwhelming to a patient. Roter (1987) indicates that even well- informed clients, such as physicians fully aware of medically relevant facts, are unlikely to retain and use this information to arrive at logical, well-considered choices among treatment alternatives. For example, health decisions made by a young teenager may simply mean decision making influenced by peers rather than professionals. In this sense, patients are left to their own devices without the guidance or consultation of a health care professional. Roter, (1987) describes this model of health care as nondirective where the patient is the dominant figure with full responsibility for and control over all decisions about his or her care. Furthermore he suggests that,

> Decision making cannot be expected to take place within a therapeutic vacuum devoid of open and thorough exchange, not only of facts, but their meaning and impact for the client's life. Meaningful assistance is not simply the

> communication of a treatment catalogue. It is the give and take necessary for an understanding of the client's perspective by the provider and an appreciation of real options and their consequences by the client (p. 28).

Brookfield (1995) describes that a guiding principle of adult education is to start with the learner's definition of need. Unlike self-directed learning in isolation, Brookfield (1995) does not indicate that the educator is restricted to the learners' perception of need. The familiar is always more safe than moving into what is unfamiliar. A "purely" self-directed approach may not challenge the learner to go beyond the expressed needs to reexamine current assumptions. In the self-management model of health care, the patient is not required to manage their health care in isolation; rather, a partnership between the patient and the health care provider is established. As a result, within the relationship the health care provider can help to guide the patient to have care needs met. Therefore, the self-management model in contrast to extreme self-direction should at minimum provide the client with a basis for effective participation in sound decision making.

2. The learner has experience.

Adults come to the learning situation with a rich background of knowledge and experience (Cranton, 1989). Furthermore, they tend to learn best when this experience is acknowledged and when new information builds on their past knowledge and experience. Knowles (1980) indicates that as people grow and develop they accumulate an increasing reservoir of experience that becomes a rich learning resource for themselves and others. Furthermore, individuals attach more meaning to learnings

they gain from experience than to those they acquire passively (Knowles). Adults are a rich resource of experience, and thus instructional techniques should utilize this resource. Accordingly, the primary techniques described in the adult education literature are experiential techniques such as problem solving, group work, case studies, role-playing simulation exercises, and discussion.

The self-management approach to health and health education is consistent with the notion that the patient has valuable experience and should actively participate in the management of health. Many self-management health education programs incorporate peer teaching strategies and buddy systems into the curriculum to enhance adult learning (Clark, et al., 1991). Successful self-management of illness or disease requires that the patient use previous experience to build on the self-management tasks required to manage health. In addition, some of the self-efficacy teaching strategies, such as modeling, performance mastery, vicarious experience, persuasion, and reinterpretation of symptoms, that are used in the self-management approach are consistent with the experiential techniques discussed in the adult education literature.

3. The learning must be relevant to life.

The adult education literature indicates that generally learners view education as the process of developing increased competence to achieve their full potential in life. They want application so they can live more effectively tomorrow. Knowles (1984) notes that most adult learners do not learn for the sake of learning, but rather to "be able to perform a task, solve a problem or live in a more satisfying way" (p. 12).

Therefore, adult learning must be life centered, task oriented, practical, and meaningful to engage the learner.

Galbraith (1991) discusses learning as a transactional process where the learner is actively involved in a collaborative, reflective, and challenging encounter that results in a change in knowledge, outlook, and/or behavior. The adult learner's life is often characterized by unpredictability. Therefore, to increase the likelihood that the new behaviors remain relevant and continue to be integrated into daily life, there must be collaboration and participation between the adult learner and the educator.

When the learning focuses on the personal problems of an individual learner, the solutions to those problems must come from his own personal values and expectations, be implemented through his personal resources and skills, and be congruent with his personal meanings and strategies (DeAmicis, 1997). The self-management model of health and health education considers all patients as unique individuals and as a result, the educational process is focused so that all the learning which takes place is relevant to the lives of each individual. Curriculum in many self-management programs uses learning strategies such as role playing, small group discussion, personalized contracting, and modeling, which personalizes the learning even more. These learning strategies foster the development of problem solving and critical thinking skills which are essential for successful self-management of chronic health problems.

4. The educator is secondly a content resource.

Much of the adult education literature describes the educator in many different roles: facilitator, guide, mentor, coach, and counselor. As a result, adult educators are

first and foremost process experts, taking the role as a content resource as secondary. This approach mirrors the self-management model as health care providers take on a more consultative, process-oriented role compared with the compliance model.

It is reasonable to expect that the role of the educator as a content resource may be significant in the beginning of the teaching and learning process (Cranton, 1989). The learner may not be able to access, understand, or integrate information from outside sources. The educator can assist the learner to screen the information, attending initially only to what is essential knowledge. In preparing the learner for independence, the educator gradually decreases input, acting more in a consulting role. As a result, the learner is prepared for later stages in the learning process such as self-direction, and is able to seek out supplemental information and sources as required.

In the self-management model, patients become managers of their health and health care. The relationship between patient and health care professional becomes more of a partnership where the patient uses health care professionals as a team of consultants. As indicated by Lorig et al. (2000) once the health care consulting team has given the individual their best advice, it is up to the individual to follow through.

5. There should be mutual planning of the program.

Adult education literature indicates that the learners should be actively involved in the process of planning their own learning using the instructor as a facilitator, guide, coach, mentor, co-inquirer, and/or resource person. Thus, the teaching and learning process is the mutual responsibility of the instructor and the learner. Adult educators require the ability to assist learners in diagnosing their needs, the formation of their

learning objectives, identification of potential resources, and devising strategies to attain the learner's goals.

Adults come to the learning situation with their own personal goals and objectives, which may or may not be the same as those that underlie the learning situation. Therefore, the adult learner prefers to be actively involved in the learning process rather than a passive recipient of knowledge (Caffarella, 1994). In addition, Caffarella indicates that learners want the opportunity to be supportive of each other in the learning process.

Each adult learner has an individual learning style for effecting change in his or her behavior and an individual cognitive style for processing information. The learner's experience and individuality must also be valued and respected, and as a result no one set of principles or guidelines can be regarded as definitive. Each instructor of adults must question and adapt to each instructional situation. As a result, when planning the education, educators must take learning style into consideration

Mutual planning is a requirement of the success of the self-management model of health care and health education. This exists due to the partnership that is developed between patient and provider and the lack of prescription from the health care professional to the patient. As such, the individuality of the patient is taken into consideration. Furthermore, in self-management health education programs, patients take an active part rather than the passive, dependent role characteristic of the compliance model.

6. The educator has a responsibility to encourage self-direction.

Educators must believe in the learner's abilities to direct their own learning (Cranton, 1992). Transfer to self-directed learning, like transfer to the self-management model is particularly difficult for educators who have a traditional teacher-centered educational background. Those in the field of health care, like education, may have certain assumptions about being a "professional" and having control over learning. As such, for some educators and health care professionals, self-direction or self-management means the loss of authority, influence, and control over another. A paradigm shift is necessary to move from the traditional models of education and health toward self-directed learning or self-management. This involves the health care professional giving support and encouragement to the patient who is attempting to assume more responsibility for their health and health care.

7. The learner must be ready to learn.

Knowles (1980) indicates that people become ready to learn something when they experience a need to learn it in order to cope more effectively with real-life tasks or problems. Common sources of readiness to learn can be thought of as "trigger events" and commonly include developmental tasks such as birth, death, or an illness. Furthermore, the adult will be most responsive to learning when a "teachable moment" arises.

Learning can be an anxiety-provoking experience and, if the anxiety is extreme, can result in a barrier to learning. The learner must balance between the desire and/or need to change or become more proficient and the fear of the unknown. The educator

must look for these opportunities and recognize that energy, motivation, and willingness to risk will be greatest at these times. In these cases, the educator is responsible for helping individuals discover their "need to know". Furthermore, Knowles (1980) suggests that it is important that programs are organized around life-application categories and sequenced according to the learner's readiness to learn.

The concept of timing is critical in the self-management model of health care and health education, especially in the case of chronic disease. Considering the nature of chronic disease and the stages that individuals with chronic conditions experience; (see Appendix A) the phrase "timing is everything" is especially relevant. For example, self-management strategies are most appropriate in the establishment phase of the crisis stage of chronic disease (Van Eijk & De Hann, 1998), as during this phase "behavior patterns will be developed which will also be of great importance in coping with the disease in general" (p. 235). Therefore, it is critical to the success of the self-management approach that health educators and health care professionals are "in tune" with the needs of individuals with chronic conditions so they can help them to discover and achieve their learning objectives.

8. The learning climate must be carefully constructed.

Adults are more receptive to the learning process in situations that are both physically and psychologically comfortable. Knowles (1984) indicates that both the physical and psychological climate must be such that learners feel at ease and are able to express themselves without fear of disrespect, punishment, or ridicule. Similarly, Brookfield (1986) indicates that an essential task of the facilitator is to set a climate for

learning in which adults feel free to challenge one another and can feel comfortable with being challenged. An integral part of the learning climate are the relationships between the learner and the educator and amongst the learners. Therefore, a relationship built on trust and respect for all individuals in the teaching and learning process is essential.

In comparison to the compliance model of health education, the self-management model is characterized by a leveling of power dynamics and more active participation of the patient. As a result, there is a shift in control from the health care professional to the patient. This shift in itself promotes an atmosphere of trust and respect. Furthermore, for this type of relationship to be successful, a significant amount of trust and respect must exist among partners. As such, both parties must feel comfortable expressing themselves in an open, honest manner.

In many ways, adult education theory mirrors self-management theory. As a result, much of the adult education literature can be applied to the health care or health education setting. Furthermore, applying adult education theory to health care and health education may help educators and professionals to adopt the self-management approach which in the case of chronic disease is essential to the well-being of the individuals living with chronic conditions and the health care system in general.

Freire and the Self-Management Model

Paulo Freire was a philosopher and educator in Brazil whose theories, like adult education, link very well to the self-management model of health care and health

education. The following describes several key concepts behind Freire's philosophy of education and the relationship to self-management.

Freire (1970) indicates that due to social, political, and economic domination and paternalism, the individuals within society are in the state of oppression. Friere described some of the basic characteristics of this form of oppression as: paternalistic, authoritative, prescriptive, and dehumanizing. Friere suggested that if individuals have been in an oppressed-oppressor relationship long enough, those who are oppressed will begin to believe in the premises within which they have been oppressed. In this situation, those who are oppressed will no longer need an oppressor to enforce oppression upon them, as they will have enconscientized their victim status, and to maintain this form of "reality" will perpetuate the forms of oppression themselves. Friere believed that all individuals wish to better themselves. Furthermore, Freire believed that if the oppressed were provided with the proper tools they would be empowered to overcome the oppressive state.

In reviewing Pedagogy of the Oppressed (Freire, 1970), the paralleled relationship between oppression and the compliance model of health education is very apparent. Furthermore, the self-management model mirrors what Freire would label and advocate as liberating education.

The compliance model of health education is similar to the banking model of education as described by Freire. In the banking model, education is regarded as the act of depositing information. Instead of communicating, the teacher issues communiqués and makes deposits which the students patiently receive, memorize, and

repeat (Freire). Furthermore, knowledge is considered a gift that is bestowed by those who consider themselves knowledgeable upon those whom they consider to know nothing. By believing in the students' ignorance, the teacher justifies his own existence. The banking model of education minimizes the students' power and tends to serve the best interest of the teacher.

The oppressive nature of the banking model of education has similar characteristics to the traditional medical model of health care and the compliance model of health education. In Pedagogy of the Oppressed (1970), Freire lists characteristics of the banking model of education which below have been modified by changing the subjects: teacher to physician and student to patient, with the intention to present the link between the compliance model of health education and Freire's educational philosophy:

1. The physician teaches and the patients are taught.
2. The physician knows everything.
3. The physician thinks and the patients are thought about.
4. The physician talks and the patients listen - meekly.
5. The physician disciplines and the patients are disciplined.
6. The physician chooses and enforces his choice and the patients comply.
7. The physician acts and the patients have the illusion of acting through the action of the physician.
8. The physician chooses the treatment content and the patients adapt to it.
9. The physician confuses authority of knowledge with his own professional

authority, which he set in opposition to the freedom of the patients.

10. The physician is the subject of the treatment process, while the patients are mere objects.

In the compliance model of health care, the professional is authoritative, paternalistic, and prescribes treatment regimes for patients. As a result, the patient loses power and remains in a passive, dependent, oppressed state. Especially in the case of treatment of chronic illness, the compliance model of health education is insufficient.

Today's health care system in many ways mirrors the banking model of education. For example, a patient in a hospital passively receives care from health care professionals who make all the decisions surrounding methods of treatment, often with little consideration of the patient as an individual. In this environment, the patient is cared for to such an extent that they tend to conform to the hospital culture- that of "they" know what is best for me. Weakness inherent in this system is that decisions are always made for patients, rather than patients learning how to make health care decisions for themselves. In the words of Freire (1970), people living in this type of oppression become enconscientized, meaning that individuals are no longer able to think and act for themselves.

The basis of health education today should focus on client–professional partnership. In learning, participation cannot be only a method of transferring knowledge, but must also be a process by which the learner gains confidence in his/her ability to solve problems. Learning strategies fundamental to health education

programs need to be characterized as learner-centered, learner-active, and requiring learner-expert collaboration.

Freire (1970) discusses the concept of liberating education where individuals are enabled to overcome the oppressive state. A central focus of Freire's work is that those who are taught and those who teach are involved as equal partners in the learning experience. According to Freire, the role of the educator is to understand and become a part of the learner's culture, to stimulate learning, and hence to "free" or empower the individual. In Freire's liberating model, the educator becomes the learner, listening to and understanding the needs of the individual. In Freire's model, learners must participate actively in the learning process, through dialogue with the instructor who assumes the role of colearner. Therefore, the educator and learner are mutually responsible for the teaching and learning process.

The basic philosophy behind the self-management approach to health and health care is consistent with Freire's educational philosophy. Self-management attempts to provide patients with the skills necessary to overcome the paternalistic relationship with health care professionals and to manage their own health and health care. In this way, patients are empowered and assume increased responsibility for their health and health care.

Freire's main assumption behind his educational philosophy was that "man's ontological vocation is to be a subject who acts upon and transforms his world, and in so doing moves towards ever new possibilities of fuller and richer life individually and collectively" (Freire, 1970, p. 12). This is a significant assumption that in many cases

limits Freire's work and similarly the self-management model. For example, in self-management it is assumed that patients WANT to help themselves. Unfortunately many individuals may not want to help themselves and, as a result, the self-management model fails. A key question is: Why do some patients not want to help themselves? Returning to Freire's work, the circumstance may be that those who are living in an oppressed state may not have the impetus to help themselves due to the oppression of the system they are stuck in. Therefore it is possible that the only way to change their desire to help themselves is to change the state of oppression. As indicated by Freire (1970), "only the oppressed can free themselves and therefore free their oppressors" (p. 28). In other words, it is only the patient who leaves the dependent relationship with the health care provider to actively self-manage who can change the oppressed state of the health care system. Self-management health education can enable individuals by giving them the tools to actively self-manage, liberating them from the oppressive aspects of today's health care system.

The consequences of participatory learning such as in self-management education are liberating and life confirming. The consequences of the omission of participation, such as in the compliance model, are oppression and alienation of the learner. When the learner or patient is viewed as devoid of knowledge and experience and is subsequently directed and advised, a fundamental error in treatment of the patient is made. At best, this approach to treatment and education is ineffective; at worst, it is dehumanizing and oppressive (Freire, 1970).

Within Freire's framework, the compliance model of health education would be regarded as oppressive. Conversely, the self-management approach gives individuals the ability to manage their health and direct their health care. This may be the patients' first step towards changing the social, economic, or environmental causes of their ill health. The similarities between the self-management approach to health education and Freire's model of liberating education are evident. Approaching chronic disease from the self-management point of view is to empower and enable the patient, with positive consequences on the health care system that are far reaching.

This concludes the review of the literature relevant to the research project. These topics will be revisited in the discussion section of this paper to help bring clarity to the results of the study. The next section of the paper outlines the methodology and procedures which were used to study the concept of self-management health education.

CHAPTER THREE: METHODOLOGY AND PROCEDURES

The purpose of this research project was to elicit and analyze experiences of participants of the Arthritis Self-Management Program in order to develop a more complete understanding of the self-management patient education approach in the treatment of chronic health conditions. This chapter serves to outline the method of this study. First, consideration is given to the use of combined research methodologies, and the use of combined methodologies within the study is outlined. Following this, the chapter continues with a description of the subjects, instrumentation, and a sequential description of the study procedures, data collection, and data analysis methods. The chapter concludes by outlining the major assumptions and limitations of the study that must be considered when interpreting the findings of the study.

A Methodological Consideration

Historically, there has been much debate in the research community regarding which type of research is "better"-qualitative or quantitative. Unfortunately, as the research setting is specialization focused, many researchers tend to take stances for one approach to research, discounting and in some cases discrediting the other. According to Bogden and Biklen (1998), no one method is the best; rather, the method should be chosen depending on what is being studied and the goals of the research.

Qualitative and quantitative methods have different inherent characteristics and strengths. Morgan (1998) discusses the notion that research projects that combine the strengths of two methods properly have the potential to produce more than those same methods could offer in isolation. In this sense, combining qualitative and quantitative methods maximizes the ability to bring different strengths together in the same research project. Furthermore, Morgan suggests that using multiple methods can assist in cross-validating the results on the same research question.

The key goal in studies that pursue complementary methods is to use the strengths of one method to enhance the performance of the other method (Morgan, 1998). Furthermore, Morgan indicates that "health researchers are particularly likely to try and connect the strengths of different methods to address the complexity of their research topics- especially when a project's goals include both pure research and applied uses in practice settings" (p. 365). Greene, Carecelli and Graham (1989) said that an important goal for complementarity is "to measure overlapping but also different facets of a phenomenon, yielding an enriched, elaborated understanding of that phenomenon," while also summarizing its purposes as seeking "elaboration, enhancement, illustration, clarification of the results from one method with the results from the other method" (pp. 258-259).

In this study, qualitative and quantitative methods were used in an effort to integrate the complementary strengths of each research method. For example, quantitative data were gathered to measure levels of self-efficacy, and qualitative interviews were held with program participants. Thus, in this project the quantitative

data added another dimension of strength to the qualitative data. In this way, information from the quantitative data (scores calculated from scales) assisted in making results from the qualitative data (answers to interview questions) more comprehensive. The outcome was richer, more meaningful data. Morgan (1998) describes this method as quantitative preliminary (quant -> QUAL) meaning that the complementary method is quantitative and preceding the principal qualitative method. In addition, Morgan indicates that this method "can guide purposive sampling and establish preliminary results to be pursued in more depth" (p. 368). Thus, in this study the knowledge provided by the small-scale use of quantitative methods was used as an adjunct to the findings of the larger qualitative aspect of the research project.

Summary of Research Methodology

As indicated above, the research methodology used in this study was a combined approach using small-scale quantitative method, followed by a more extensive qualitative method. Specific methods used are descried herein.

Quantitative methods in the form of scored questionnaires were used to measure levels of self-efficacy to self-manage chronic arthritis (see Appendixes G and H). These measurements provided valuable information which thereby enhanced the findings of the qualitative part of the study.

A qualitative phenomenological research methodology was the main focus of the study. Phenomenology seeks to "understand the meaning of events and interactions to ordinary people in particular situations" (Bogden & Biklen, 1998).

Furthermore, phenomenology seeks to answer the question, "What is the essence of the experiences of this phenomenon for these people?" (Quinn Patton, 1990). The phenomenon that was studied in this research project was the self-management approach to health education and the treatment of chronic illnesses. This form of methodology was chosen as the principal method as it seemed to fit well with the nature of the problem and the research questions posed.

Sample and Selection of Participants

The study sample consisted of participants of the Arthritis Self-Management Program (ASMP) in the greater Toronto area. The ASMP is a self-management community-based program that is organized and implemented by the Canadian Arthritis Society. Due to low enrollment and participation in the courses, recruitment of subjects for the study was required from two separate programs. These programs were timed 2 weeks apart and were located within a 50 kilometres of each other.

The study sample consisted of 7 volunteer participants of the ASMP: 2 from the first course and 5 from the second course. Between the two courses, 4 individuals refused to participate for reasons such as time constraints, inconvenience of the course location, and health restrictions. The sample size is deliberately small to allow for in-depth, rich descriptions from each participant during the period of study. All of the 7 participants were female and were between the ages of 29 and 74. All participants were able to attend at least five out of six sessions of the ASMP.

The study sample is purposive. Participants were selected as they had the lived experience of learning self-management of a chronic arthritic condition. According to Quinn Patton 1990, purposive sampling allows for information rich cases to be studied in depth. Furthermore, sampling of this type allows the researcher to gain a perspective from the insider. This perspective then allowed the researcher the opportunity to obtain valuable information pertinent to the purpose of the research study.

Instrumentation

Instruments used in this study included the visual analogue scale (see Appendix G) and the perceived self-efficacy scale (see Appendix H). The visual analogue scale is a 10 centimeter line which was used to measure participants' self-efficacy. For example, participants were asked to indicate on the 10 centimeter line how confident they were to manage their arthritic condition. The visual analogue scale has been shown to be reliable and valid in rating pain, general health status, fatigue, quality of life, grip strength and functional capacity (Lorig, 1996). Scoring of the visual analogue scale followed the instructions indicated by Lorig, (1996) and are described in detail in the Data Analysis section of this chapter.

The perceived self-efficacy scale (Lorig, 1996), was used to measure the participants' confidence in their ability to self-manage their arthritis. This scale has been shown to be reliable and valid in measuring perceived self-efficacy (Lorig, 1996). The test-retest reliability coefficients ranged from .82 to .89, and internal consistency

coefficients from .77 to .92 (Lorig, 1996). Construct validity of all subscales ranged from .72 to .92 Lorig, (1996). Thus, the reliability and validity of all the self-efficacy subscales is adequate.

The scale is made up of a variety of subscales which are characterized by the following headings: a) self-efficacy to perform self-management behaviors, b) self-efficacy to manage the disease in general, and c) self-efficacy to achieve outcomes. Scoring of the scale followed the instructions as indicated by Lorig, (1996) and, like the visual analogue scale, are outlined in the Data Analysis section of this chapter.

Procedures and Data Collection

Approval for the study was obtained from the Arthritis Society of Canada and the Brock University Ethics Review Board (see Appendix B). After confirmation of the approval was obtained, the study was initiated.

Approximately one month prior to the start of the course, the researcher obtained the name and telephone number of the course instructor and a list of the program participants' names and addresses from the Arthritis Society. In addition, the course instructor was contacted by the Arthritis Society to introduce the study and receive approval from the instructor. Two weeks prior to the start of the course, the researcher contacted the instructor to introduce the study in more detail, discuss any questions or concerns, and work out the logistics of the data collection on the first day. As well, an introductory letter was sent to all course participants one week prior to the

start of the program with the intent to introduce the researcher and the research study, and to invite them to take part in the study (see Appendix C).

During this initial phase of the study, a research problem arose: only 5 people attended the first day of the program. Although the study design did not require large numbers of participants, it was evident that another ASMP would need to be included in the study. Fortunately, the Arthritis Society was running another ASMP in the same region to start 2 weeks later and agreed to have the researcher work with the second group as part of the study. The same protocol was followed with the course instructor and ASMP participants as in the first group, yet some significant differences were evident. When speaking with the course instructor of the second group on the phone a few weeks prior to the start of the program, the course instructor urged the researcher to take part in the program. She said, "How could anyone write about the program if they had not taken part in it?" Upon reflection of writings by Quinn Patton (1990) on qualitative research methodology, participation in the course would enable the researcher to develop a relationship with the study's subjects, and therefore would potentially produce richer data. Therefore, considering the instructor's request and the participatory nature of qualitative research, the researcher decided to take part in the second course. Despite this significant difference, the protocol for each program was identical and is described herein.

On the first day of each course, the researcher introduced herself and gave the group a more detailed description of the study (Appendix D), discussed the purpose of the research, and invited the course participants to participate in the study (see

Appendix C). Upon receiving written informed consent from each participant (see Appendix E for consent form), the study participants completed a general information form (see Appendix F) and two questionnaires: the visual analogue scale and the perceived self-efficacy scale (see Appendixes G and H). During the completion of these scales, the researcher was available to individually answer questions posed by study participants and therefore help to clarify the focus of the questionnaires. After collecting the completed scales, the researcher reiterated the rest of the study procedures.

Data collection continued on the final day of the course. The researcher distributed the same two questionnaires to each participant, and after collecting the completed questionnaires, the researcher discussed the procedures for the interview component of the study, distributed a list of potential interview questions, and set up interview times with each participant.

Up to 2 weeks after the end of the ASMP, the researcher conducted individual interviews with each study participant for approximately 45 minutes, with the focus on the participants' course outcomes and individual's beliefs about the self-management approach to the treatment of chronic arthritis. The interview followed the style of a standardized open-ended interview (see Appendix I for sample interview questions). As described by Quinn Patton (1990), "the exact wording and sequence of questions are determined in advance. All interviewees are asked the same questions in the same order. Questions are worded in a completely open-ended format" (p. 288). According to Quinn Patton, benefits to this form of interview include:

1. Increased comparability of the responses and completeness of data for each person on the topics addressed, as respondents answer the same questions.

2. Increased focus of the data collected.

3. Facilitation of organization and analysis of the data.

After the interview, each participant was informed that they would be contacted once in the future by mail from the researcher to inform them of the results of the study and to invite them to attend a presentation of the results to the Arthritis Society at the head office in Toronto, Ontario. After each interview, the researcher thanked each individual for participation and then encouraged the participant to contact her if they had any further questions or concerns about the research.

Data Analysis

Data analysis for the quantitative part of the study included reviewing the visual analogue scales and the self-efficacy scales recorded both prior to the course and upon course completion. The visual analogue scales were scored according to Lorig (1996) meaning that the mark made by the participant on each scale was measured with a ruler to the nearest 0.5 centimeter. This number was scored out of 10 and converted into a percentage for ease of analysis.

The self-efficacy scale was scored according to Lorig (1996), meaning that the scores for each subscale were added and converted into a percentage. Further, the scores from each of the self-efficacy subscales were added up and then converted to a

percentage, producing an overall self-efficacy score. The sub and total self-efficacy scores as percentages are presented in Chapter Four.

The process of data analysis for the qualitative part of the study followed the procedural steps outlined by Quinn Patton (1987). Specifically, the researcher made transcriptions of the interviews and read each one several times to achieve a sense of the whole interview. Following this, the researcher condensed all of the raw data from each transcription by constructing a case record for each participant. To make each case record, the researcher re-read each transcription and, as part of this process, themes from the data emerged. The case record was then organized in such a way that the raw data (quotes from each participant) were edited according to a variety of themes which had emerged from analyzing each of the transcriptions.

After analyzing each case record individually, a cross-case analysis was completed. This was done by reading each case record and developing a final set of themes from each participant's perspective about self-management and the treatment of chronic conditions that were consistent across the case records. The themes from the case records were then organized as a cross-case summary or as Quinn Patton (1990) labels, a case study narrative. One individual had largely different beliefs compared to the rest of the group and, as such, these insights were included in the cross-case summary and labeled as orphan beliefs. The various themes that emerged from the cross case summary are the findings of the study and are reported in detail in Chapter Four of this paper.

After developing the themes from the qualitative data analysis, the quantitative data were analyzed against the qualitative data. Specifically, each individual case record and corresponding self-efficacy scores, both pre- and postcourse for each participant were compared and analyzed. This process led to the findings also presented in Chapter Four of this paper.

Methodological Assumptions and Limitations

A variety of assumptions and limitations of the study must be addressed and explained. First, consideration must be given to the assumptions inherent in this type of qualitative research. For example, within the interview style of qualitative research it is assumed that the answers given by each participant are an accurate representation of their values and beliefs. It would be very difficult to confidently tell if participants were being dishonest or providing information with the intent to please the researcher or hide beliefs which were contrary to what was learned from the course. Furthermore, answers to the research questions may be skewed depending on the individual's state of mind on the day of the interview. For example, if the symptoms of the disease were worse than normal, a particular subject's answers to interview questions may be more negative and therefore not an accurate representation of their thoughts about self-management.

The validity of qualitative research relies to a great extent on the researcher's skill and competence. For example, it could be easy for the researcher to bias the results by asking questions that emphasize certain variables or interpreting data

according to personal values. To ensure accurate results, the researcher in this study took time to identify personal beliefs about patient education and self-management of chronic conditions prior to the start of data collection. In addition, during data collection and analysis the researcher was conscious to bracket or suspend her personal beliefs in order to get an accurate representation of the beliefs of the sample. In this sense, the researcher refrained from guiding the participants in their answers and asked only open-ended questions. Furthermore, interview questions were checked by experts and modified as needed to avoid ambiguity

As the study included both qualitative and quantitative methods, it was also critical that the qualitative data collection and analysis were not skewed by the preliminary quantitative results. Before data collection commenced, the researcher was conscious of this potential conflict and therefore suspended any beliefs about participants from information gained from the preliminary quantitative findings.

Another assumption of the study was related to the quantitative aspect of the study. The scales that were used in the quantitative aspect of the study were shown to be reliable and valid (Lorig, 1996). As the scales had not been specifically pilot tested for these particular subjects, it was assumed that the scales would produce accurate results.

As two different groups of the ASMP were included in the study, it is assumed that these two groups were equal. This is a significant assumption, especially considering the fact that there were two different instructors each of whom may have had their own style and strengths as leaders. Similarly, as the researcher participated in

one of the courses, the subjects may have had a different relationship with the researcher and thus, considering the nature of qualitative research, may have changed the results. Before the start of the programs, the researcher was aware of this discrepancy between the courses, and as such made a conscious effort to keep the interview procedure as consistent as possible among all the study participants.

This study assumes that all self-management patient education is like the ASMP and that the ASMP is a good example of the self-management approach to patient education. As a result, the results presented in this study are not generalizable to all self-management health education programs or to the self-management model. The results that are presented are the realities of a group of individuals who participated in one form of a self-management health education program.

This concludes the discussion of the methodology and procedures of the study. The focus of the paper now turns to the findings of the research project, which are discussed in detail in Chapter Four.

CHAPTER FOUR: FINDINGS

The focus of this chapter of the project is to present the results of the research study. First the quantitative and qualitative results will be presented in separate sections. Within the qualitative section, the relationship between the results of the two research methods will be integrated. To conclude the chapter, a summary of the results is provided.

Quantitative Findings

The questionnaires used to obtain the quantitative data measured levels of self-efficacy to self-manage a chronic disease, which in this study was chronic arthritis. These measurements were taken before and after the course. The first questionnaire used was a self-score measurement of self-efficacy using a visual analogue scale. The second questionnaire used to measure self-efficacy was Lorig's self-efficacy scale (Lorig, 1996). As the second questionnaire has been shown to be reliable and valid for other studies of the ASMP, scores from this scale were used as the definitive scores of the study and as such will be reported first. Results of the visual analogue scale will be highlighted briefly at the end of this section, as it was not the primary scoring instrument of the study.

The Self-Efficacy Scale

Lorig's self-efficacy scale is comprised of three subscales including: a) Self-Efficacy to Perform Self-Management Behaviors, b) Self-Efficacy to Manage the Disease

in General, and c) Self-Efficacy to Achieve Outcomes (Lorig, 1996). The scores from the scales are presented in Table 1 in the form of percentages which were calculated from the participants' completed questionnaires. Specifically, this table presents the scores of the subscales which are listed as SUBSCORE A, B, and C. These subscales were then used to calculate a total self-efficacy score, which is listed as TOTAL SCORE in Table 1.

Analysis of the subject's precourse total scores suggests that 4 participants (see Table 1, Subjects 3, 4, 6, and 7) scored high on the precourse self-efficacy total scale (high self-efficacy is defined as greater than 65% on the total score). Conversely, 3 participants (see Table 1, Subjects 1, 2, and 5) scored low on the precourse self-efficacy total scale (low self-efficacy is defined as less than 65% on the total score). Postcourse data indicate that the course enhanced the self-efficacy scores of all 4 of the participants who had started the course with a high level of self-efficacy (see Table 1, Subjects 3, 4, 6, and 7). Furthermore, 2 of the subjects with low levels of self-efficacy before the course scored high self-efficacy to manage their arthritis after the course (see Table 1, Subjects 2 and 5). It is important to note that the two individuals who made the transition from a low level of self-efficacy before the course to a high level of self-efficacy after the course had increases of 19% and 22% (see Table 2, Subjects 2 and 5).

The rest of the participants' levels of self-efficacy to manage their arthritis changed less dramatically: between only 4 and 8% (see Table 2, Subjects 1, 3, 4, 6, and 7).

TABLE 1

Self-efficacy scores

Subject	Precourse scores (%)		Postcourse scores (%)	
1	Subscore A	57.270	Subscore A	58.180
	B	52.000	B	54.000
	C	53.120	C	42.500
	Total score	54.375	Total score	49.687
2	Subscore A	74.540	Subscore A	83.630
	B	78.000	B	88.000
	C	40.625	C	70.000
	Total score	58.125	Total score	77.500
3	Subscore A	75.450	Subscore A	83.630
	B	78.000	B	80.000
	C	73.750	C	78.750
	Total score	75.000	Total score	80.625
4	Subscore A	81.810	Subscore A	82.720
	B	80.000	B	84.000
	C	74.280	C	86.250
	Total score	78.000	Total score	84.680
5	Subscore A	60.900	Subscore A	84.540
	B	82.000	B	86.000
	C	54.375	C	79.375
	Total score	60.937	Total score	82.180
6	Subscore A	62.720	Subscore A	77.270
	B	70.000	B	76.000
	C	83.750	C	88.750
	Total score	74.375	Total score	82.810
7	Subscore A	84.540	Subscore A	89.100
	B	90.000	B	94.000
	C	83.750	C	88.750
	Total score	85.000	Total score	89.680

Table 2

Individual Changes in Total Scores

SUBJECT	Precourse total score (%)	Postcourse total score (%)	Change in scores
1	54.375	49.687	-4.680
2	58.125	77.500	**+19.375**
3	75.000	80.625	+5.625
4	78.000	84.680	+6.680
5	60.937	82.187	**+21.25**
6	74.375	82.810	+8.435
7	85.000	89.680	+4.680

One participant (see Table 1, Subject 1) with low self-efficacy before the course scored lower on the postcourse self-efficacy scale. This reflects that the individual's low level of self-efficacy to self-manage their arthritis was not improved despite the efforts made in the course.

Statistical analysis of the change in the group of participant's overall self-efficacy in relation to the self-management course was then completed. Using the data presented in Table 1, means and standard deviations of pre- and postcourse levels of self-efficacy were computed for each subscale and total score (See Tables 3 and 4). Differences between the means were analyzed using paired t tests (see Table 5). Scores were analyzed as continuous variables. Results which are presented in Table 5 indicate a significant change in the level of self-efficacy precourse versus postcourse when combining the three subscales to produce one total self-efficacy score ($t=-2.591$, $p<0.05$). When comparing the subscales individually, a significant difference was found on two of the three subscales (see Table 5). Testing indicates that the group's self-efficacy to perform self-management behaviors (subscale A) and to manage the disease in general (subscale B) were significantly influenced by the course ($t=-2.976$ and $t=-4.382$ respectively, $p<0.05$). Results indicate that there was no significant change in the third subscale which measured the group's self-efficacy to achieve outcomes ($t=-1.970$, $p<0.05$). Considering these results, it is evident that overall, individuals felt more confident to actually perform the behaviors that helped them to self-manage after the course. In addition, the course changed the participants' confidence to manage their arthritis in general. For example, they may have felt more able to do the

Table 3

Paired Samples Statistics

	MEAN	N	STD. DEVIATION	STD. ERROR MEAN
Pair 1				
Prescore A	71.0329	7	10.7362	4.0579
Postscore A	79.8671	7	10.1703	3.8440
Pair 2				
Prescore B	75.7143	7	12.0238	4.5446
Postscore B	80.2857	7	12.9321	4.8879
Pair 3				
Prescore C	66.2357	7	16.8494	6.3685
Postscore C	76.3400	7	16.3637	6.1849
Pair 4				
Pretotal	69.4029	7	11.5318	4.3586
Posttotal	78.1657	7	13.1024	4.9522

Table 4

Paired Samples Correlations

	N	Correlation	Sig.
Pair 1 Prescore A and Postscore A	7	.699	.080
Pair 2 Prescore B and Postscore B	7	.978	.000
Pair 3 Prescore C and Postscore C	7	.667	.102
Pair 4 Pretotal and Posttotal	7	.743	.056

Table 5

Paired Samples Test

	Paired Differences					t
	Mean	Std. Deviation	Std. Error Mean	95% Confidence Interval of the Difference		
				Lower	Upper	
Pair 1 Prescore-Postscore A	-8.8343	8.1264	3.0715	-16.3500	-1.3186	-2.876*
Pair 2 Prescore-Postscore B	-4.5714	2.7603	1.0433	-7.1242	-2.0186	-4.382*
Pair 3 Presocre-Postscore C	-10.1043	13.5682	5.1283	-22.6528	2.4442	-1.970
Pair 4 Pretotal-Posttotal	-8.7629	8.9478	3.3819	-17.0382	-.4875	-2.591*

$p < 0.05$

*Significant Difference

Table 6

Paired Samples Test

	Df	Sig. (2-tailed)
Pair 1 Prescore-Postscore A	6	.028*
Pair 2 Prescore-Postscore B	6	.005*
Pair 3 Prescore-Postscore C	6	.096
Pair 4 Pretotal-Posttotal	6	.041*

$p < 0.05$

* Significant Difference

different tasks required to help them cope with their disease. Results indicate that the course did not significantly change the participants' confidence to achieve outcomes. This suggests that overall, the individuals in the group did not feel more able to manage or change the symptoms associated with the disease or change their confidence in their ability complete their normal activities of daily living.

The Visual Analogue Scale

The visual analogue scale (VAS) was used in this study as an adjunct to Lorig's self-efficacy (SE) scale. This was done to test the internal consistency of the scales. The visual analogue scale is a self-report scale, whereas Lorig's self-efficacy scale is a more elaborate and detailed scale. The VAS as a self-report scale is useful as it is based on the lived experience of those who are living with the condition and as such have a greater understanding. Considering these differences, the scores of the different scales have the potential to reveal different aspects of self-efficacy.

When comparing the VAS scores to the SE scale scores precourse, all VAS scores were high, whereas the SE scale scored only 4 participants as high and 3 participants as low (see Table 7). This discrepancy in the scores of the different scales precourse indicated to the researcher that either some participants were poor judges of the self-efficacy as they overestimated their confidence to self-manage or the self-efficacy scale used was not an accurate representation of the individuals' self-efficacy. The latter explanation is less likely, as the Lorig scale has been shown to be reliable and valid for ASMP participants.

Table 7

The VAS and SE Scores Pre and Post-Course

SUBJECT	VAS Precourse (%)	VAS Postcourse (%)	SE Scale Precourse (%)	SE Scale Postcourse (%)
1	83*	**43**	**49.687**	**54.375**
2	76*	75*	**58.125**	77.5*
3	81*	74*	75*	80.625*
4	75*	78*	78*	84.68*
5	89*	80*	**60.937**	82.187*
6	88*	81*	74.375*	82.81*
7	81*	91*	85*	89.68*

*Represents high score

The same comparison of the scales postcourse revealed that all individuals with high scores on the SE scale scored high on the VAS and similarly, the individual who scored low on the SE scale also scored low on the VAS. This congruence between scales postcourse indicates that individuals may be better able to judge their confidence in their abilities to self-manage their arthritis postcourse. Again, this suggests that the VAS precourse may not have been an accurate representation of the individuals' self-efficacy, whereas postcourse the VAS was more accurate. As such, precourse it was more difficult for participants to accurately judge their self-efficacy without the guidance of the more detailed Lorig questionnaire. Postcourse, individuals were better able to judge their self-efficacy and as such the VAS was scored more realistically than before the course. Therefore, this increased accuracy may indicate that learning occurred as a result of the course.

The results of the quantitative analysis will be further highlighted and integrated with the qualitative results of the study later in this chapter and in the discussion section of this paper. The next focus of this chapter is the qualitative findings of the study.

Qualitative Findings

A large amount of information arose from the qualitative part of the study. Much of the information gathered from the qualitative data helped to answer the questions presented in the introductory section of this paper. The qualitative findings

of this research study will be presented under the following headings, which represent the themes that emerged from the data:

Outcomes of the Arthritis Self-Management Program (ASMP).

Reasons for Poor Course Outcomes.

Reasons for Low Enrollment and Participation in Self-Management Health Education Programs.

Ways to Improve the Course and Increase Participation in Self-Management Health Education Programs.

Emotions and Their Impact on Adopting the Self-Management Approach.

Learning Self-Management.

Beliefs About the Health Care System and the Medical Profession.

Profile of the Self-Manager.

Outcomes of the Arthritis Self-Management Program (ASMP)

Through the interview process, descriptive outcomes related to the course were captured from the participants of the ASMP. Overall descriptions of the participants' course outcomes were very positive. Four participants described their outcomes from the course as excellent, 2 described their outcomes as good, and 1 participant indicated that she had poor outcomes.

Individuals with good and excellent outcomes described how the course helped them. The following is a list of benefits that the participants felt they gained from the course:

- Improved outlook and attitude.
- Increased motivation.
- Decreased pain and/or better able to manage the pain.
- Increased coping.
- Increased control over the illness.
- Increased confidence to manage the illness.
- Decreased fear.
- Increased well-being.
- Increased knowledge and understanding.
- Better relations with their health care providers.
- Enhanced skills to overcome any limitations.
- Improved problem-solving abilities.
- Validated feelings and answered personal concerns.

When discussing the outcomes of the course, one participant summarized:

> After I took the course, now knowing how to deal with it is different. I can cope with it better, there are now ways and means by which I can deal with it better, like it is more controllable. I can deal with it in a positive way.

As part of the program, the instructor on the first and final day asked the course participants (second course only) the question, "What does having arthritis

mean to you?" Individuals in the group discussed this question on both days, and the instructor used a flip chart to record the highlights of the group's input. The researcher received these documents on the final day of the course, and the data have been made into a chart presented in Table 8. These documents are very useful, as they summarize the participants' viewpoints about course outcomes.

Despite the benefits listed above, individuals who described their outcomes as good felt that the course would have been more helpful if they had participated in the course closer to the time that they were diagnosed with arthritis. For example, when describing the benefits of the course, one participant said, "I think the course is beneficial, especially if you are newly diagnosed." She added, "It is almost 2 years now, it is almost no good to me. I needed this course 2 years ago when I was first diagnosed." Another participant who also had good outcomes suggested, "I would have taken it years ago if I had known the challenges of my illness." Later in the interview she added,

> Because I have had it for so long before I took the course, I sort of knew what I could do and what I couldn't do, before I got there. It would have been different if this (self-management) was a new thing, like if I had never heard of it before.

One participant who stated she had excellent results validated the responses given by those with good outcomes, indicating that the course should be taken right away after diagnosis. Her words were, "The sooner the better."

Table 8

What Arthritis Means To Me: Answers of Group 2 on the First and Final Days of the Course

June 13, 2000	July 18, 2000
➢ Pain	➢ Changes of lifestyle
➢ Uncertainty	➢ Not life threatening
➢ Fear of being incapacitated	➢ Not let it interfere with my life
➢ Limitation: activities (general and day to day)	➢ Speaking less about it (need to)
➢ Negative lifestyle changes	➢ Resting more- need to pace myself
➢ Forced changes: had to resign from job	➢ Be good to yourself
➢ Impact on financial resources	➢ Take advantage of the times when you feel good and rest when you don't
➢ Depression	➢ People are a little less serious about their arthritis- a little more laughter
➢ Frustration re: getting a diagnosis	➢ Disease seems more manageable
➢ How others relate to "me" (friends, family and strangers)	➢ Taking medication is not the end of the world

The individual who stated that her outcomes were poor indicated that the course was not very helpful to her. She stated that although she was unsure of what was missing in the course, she did not feel she got what she wanted. She said, "I'm not really sure exactly what I wanted, but I didn't get out of it what I wanted." Furthermore, she stated that the course did not change her symptoms or her ability to manage the illness. She said, "I don't really think it has changed, I don't think the course has made any difference in any way." Later in the interview she went on to say, "The course gave me some strategies for trying to help, but yea, it didn't change anything, it is still a big pain in the neck."

When reviewing the quantitative data and integrating it with the qualitative data, all individuals with good and excellent outcomes scored high levels of self-efficacy to self-manage their arthritis after the course. Conversely, the participant who suggested she had poor outcomes was the same individual who tested as having low self-efficacy to self-manage her arthritis both before and after the course. These findings are consistent with the literature that states that increased self-efficacy is responsible for enhanced course outcomes (Lorig et al., 1996). This relationship between outcomes and self-efficacy will be reported throughout this chapter and discussed in detail in the final chapter of this paper.

Reasons for Poor Course Outcomes

All participants were asked why they felt some individuals did not have good outcomes or work well with the self-management approach to treating chronic health

conditions. Responses from all 6 individuals with either good or excellent outcomes are described herein. The participant with poor outcomes from the course is not included in these findings, as she was unable to describe why she had not worked well with the program and the self-management approach.

Participants suggested that individuals would not fare well with the self-management approach if they were not motivated to help themselves. They suggested that being a good self-manager has a lot to do with one's personality and attitude towards the illness and life in general. They suggested that individuals who generally have a negative outlook on life would probably not have good outcomes if attempting to use self-management. Furthermore, they suggested that individuals whose beliefs were "cure focused" rather than focused on managing the condition are not suited to self-management. These findings will be outlined in detail later in the results section of this paper under the heading Profile of the Self-Manager.

Reasons for Low Enrollment and Participation in Self-Management Health Education Programs

During the interview process, all participants reflected upon reasons why some individuals with chronic illnesses would not choose to participate in self-management health education programs. Many participants indicated that some individuals might not know the benefits of the programs. For example, one individual said, "I think that they don't understand enough of what they may get out of it and also maybe some people are afraid to be part of the group. To be seen as sick." Similarly, many

individuals said that it is possible that some people who are diagnosed with chronic illnesses do not think that the program will do anything or be of any help. Although the participants themselves did not feel this way, through their life experiences they knew people who did feel that way. For example, one participant said, "Maybe not thinking it is going to help. Like it is a waste of time. I know that was my Mom."

Most participants believed that not participating was related to an individual's personality. Participants agreed that there are certain types of people who are unwilling and uninterested to learn. They suggested that some individuals are not motivated and are dependent on other people and medications. Participants felt that individuals with this type of personality are not the type to self-manage and, therefore, not the type to participate in self-management programs. One participant said, "I just think a lot of people are just unwilling to learn and broaden their horizons. And they feel better about feeling sorry for themselves rather than doing something about it." Another individual said, "Maybe there is too much dependence on their doctors or medications," and added further, "Maybe, they weren't motivated enough to come." From what they said, those who tend to participate in health education programs are those who have some ability or interest in self-management. This point will be discussed further in the chapter under the heading Profile of the Self-Manager.

Many participants felt that people might not participate in self-management health education due to time restraints and the hectic pace of life. Although this was a theme that emerged in the interviews, most participants said that this was not a good reason for lack of participation. Participants interviewed seemed to value their health

care and well-being and felt that taking the course was worth adjusting your schedule. It seems they felt that lack of time was used as an excuse for lack of participation. For example, one participant with excellent outcomes said,

> Maybe people don't have time, I think that is probably the major thing. You know people just don't have time, they just need to find time. Guess I just made the time, I just said this is important. And I came to every class and I am glad I came because it helped.

Again this quote is an excellent example of the notion of certain self-management beliefs and attitudes which will be discussed in detail later in this chapter under the heading Profile of the Self-Manager.

Most participants suggested that another reason for the lack of participation in programs was as a result of emotions associated with having a chronic illness. They commented that many people might not participate as a result of emotions such as fear and denial. They suggested that some individuals might be fearful of the unknown or afraid to admit that they have a problem. One participant commented on the lack of participation: "Maybe fear of the unknown, they don't know what to expect." Another participant explained, "Because they are afraid to talk around other people." It was also suggested, "Well I think fear is perhaps one of the things that prevent people from looking after themselves." Another participant said, "Umm, well I think some people are just afraid to go, they are afraid to talk about their disease. And if they go they are admitting that they have a problem, right?" In addition to the emotion fear, this quote illustrates that many individuals may be in denial about their

illness. Participants of the study suggested that denial of health-related problems is very common among their peers. Two individuals agreed that they felt denial of health problems was especially common among men. For example, one participant commented, "And men tend to be in denial about health related problems, I certainly thought that with my husband and my son too!" Another individual said,

> There is a certain amount of denial, some people think they are going to get better. Or they are afraid of what they are going to learn, and I thought just the opposite, because I discovered that this is ok, you know, that I can get on, and that the more I exercise the better. That was something I was concerned about because I didn't want to damage myself. But to find that exercise was the key, is terrific! It really is because I have a lot of things I like to do.

This quote is an excellent illustration of the notion that fear and denial restrict many individuals from participating in chronic disease self-management programs, yet overcoming that fear and denial and participating in self-management health education can result in eye-opening and world-changing opportunities.

All participants interviewed agreed that a reason for the lack of participation was lack of availability of programs. Simply, many felt that the public might just not be aware of the programs and therefore participation in programs was low. Many suggested that more advertising and marketing to health care professionals and the community might increase enrollment and participation. Similarly, one participant indicated that, considering the amount of health information currently available to the general public, people may be going to other sources to get educated. She said, "I

think that part of the thing is that a lot of the people think they can get the information from a book or the library or the Internet now."

Ways to Improve the Course and Increase Participation in Self-Management Health Education Programs

Although this was not a specific research question to be answered, many participants discussed ways to change the course and increase participation during the interview process. When asked how they would improve the course, most individuals stated that they really liked the course and that there was nothing that needed to be done to change it. Comments like, "Nothing, it was a great course," and "Actually the course was great in itself" gave the researcher the impression that participants found the course to be without major flaws.

When the researcher probed further, participants did have a few suggestions as to how the program could be enhanced. A few individuals suggested increasing the class size. Especially individuals who had good and poor outcomes felt that increasing the class size would allow for more people to share their thoughts and experiences, and that this would have been beneficial to their experience and in turn enhance their outcomes. One participant suggested that the course could have been improved by "increasing the size so there was a greater number of people to connect with, a larger class." Another participant who described herself as having had good outcomes from the program commented, "I wanted to meet other people who had rheumatoid arthritis. To see how they managed and see how they did. And that disappointed me

because there was no other person in the class with RA." This quote also illustrates the importance of sharing and support in learning to manage a chronic illness.

Many individuals interviewed felt the course should have been longer. They described the need for more sessions and increased amount of time per session. Many individuals in the program felt that extra time would have allowed the group to cover more material. Although most individuals interviewed felt there was the right amount of information presented, a few individuals would have liked more. One stated, "I would have liked more handouts and specific medical information, like maybe articles from a medical journal about the latest research. Or even a suggested reading material list, yea, like an additional reading list." Another participant commented, "The program is too short and they try to cover so much in a small amount of time... and there wasn't enough time to really talk and discuss the self-management stuff."

Individuals felt that more time would have allowed them to get to know each other a bit better. One individual commented, "If it could have been a bit longer. I think make it more sessions, maybe 2 or 3 more sessions. I think it would be good, because our time was limited, if we have more sessions it would have helped." Many participants felt that more time overall and per session would have allowed them more discussion time. One participant said, "It just seemed that our time was limited, it would have been nicer if we could have discussed things further." Another individual commented that more time per class was needed. She said, "Like what I found, and maybe other people in the group found this too, was that there was not enough time to talk to each other and get feedback from each other." These quotes indicate the

importance of process in health education programs. For example, individuals in the study valued group interaction and discussion. These ideas will be reported in detail later in this chapter under the title Learning Self-Management.

Many individuals felt that support after the program would have been helpful to them. Many participants interviewed suggested that ongoing support in the form of a support or interest group would be an asset and help them to continue self-managing. Follow-up in the form of a newsletter or mail- out was also suggested as a good way to keep in touch and promote ongoing self-management. One individual stated that she thought follow-up would be a good idea. She said, "I would have liked that [follow-up], actually I plan to attend again in some capacity for more support."

As mentioned earlier in the Outcomes of the ASMP heading of this chapter, both participants who felt they had only good outcomes suggested the main reason for the outcomes was the timing in which they took the course. Both individuals indicated the importance of taking the program soon after diagnosis. Both individuals said that their outcomes from the course would have been much better if they had taken the course earlier. One participant said, "A lot of the stuff that I heard was not new to me. So I think the course is a good thing to have, but it is important to get people to it." Another individual suggested that the course should be taken within the first 3 to 6 months of being diagnosed. She suggested that the course would help newly diagnosed people get a lot of information quickly. She reported that she had been diagnosed 2 years earlier and she had to learn through her own reading and

appointments with professionals, both of which can take a lot of time and are not cost effective for the health care system. She explained,

> Every specialist you have to wait at least 6 weeks for. And this was a 6 week course, so I could have been through that, and known so much more, so that when I saw a specialist I would have been able to ask better questions, because I would have had the basic questions answered.

In light of these quotes, participants indicated that when promoting the course the concept of "timing" was essential to explain to potential participants and the health care professionals who are referring them to the program.

One individual who had poor course outcomes and low self-efficacy to self-manage made a variety of comments that suggested she thought the course could be improved if the instructors of the course were health care professionals rather than lay persons. Although this belief was not held by any of the other participants, it has been included in the results, as it was a strong theme in this particular individual's case. Again, this was the particular individual who subjectively reported having poor course outcomes and objectively tested as having low self-efficacy to manage her arthritis both pre- and postcourse. Ideas surrounding this belief will be discussed in detail later in this chapter under the heading Learning Self-Management.

Emotions and Their Impact on Adopting the Self-Management Approach

Through the interview process, it appeared that a common theme in the data was the role of emotions and emotional stages associated with chronic disease.

Furthermore, it appeared that the emotions related to living with chronic arthritis influenced the ability of the individual to adopt self-management strategies into their life.

First, all individuals described feeling a variety of emotions before, during, and after diagnosis of their chronic arthritic condition. Individuals, when first diagnosed with chronic arthritis, described feelings such as: uncertainty, confusion, fear, disappointment, anger, frustration, and depression. For example, when describing how she felt before being diagnosed with arthritis, one individual said, "I stopped doing everything and so I was just waiting for my test results and I was really scared because I had never had so much pain." Similarly another individual recounts, "I know when I was first sick, before I got diagnosed I kind of felt like there was no way out. I really started to feel sorry for myself." Another participant shared her experience of being diagnosed:

> My doctor didn't know what it was, she said it could be this or this or this or this. And so it was very scary. So then when I found out it was arthritis and then I learned about it through the course, I found that it was not terrible.

Some individuals described having a hard time accepting the diagnosis, which caused them to feel sorry for themselves. They described how at times they felt helpless and like there was no hope. All individuals but one stated that although they felt these emotions for varying amounts of time, they were able to transcend through these negative emotions. Most individuals labeled this transition as acceptance of the illness. They indicated that you must accept the illness in order to live with it. One

individual described this transition as a change in her mentality from "complaining to doing" and indicated she realized she had to start taking care of herself and get control of her life and the disease.

Many individuals suggested the importance of support in this transition. Most people interviewed commented that education is one form of support that helps the individual accept the disease. One individual said,

> I think health education is important because it brings knowledge. Knowledge of what is really happening, especially for people who don't have a health background. Like if they know what is exactly going on inside of their body, they will know what they can do and they will be more accepting of their limitations and they will be able to cope more and be able to deal with it without being angry.

Many individuals suggested that education showed them that they were not the only one with arthritis and that their problems could be worse. For example, one individual described how the course had helped her to accept her arthritic condition. She explained,

> I got over any kind of fear I had of it, I know where to go if things get worse. It gave me a great sense of well-being and the exercises that were suggested helped, let alone alleviated any pain. But also, I liked to know that there are an awful lot of other people out there, you know, and it sort of makes it a lot easier to deal with.

It seemed the course showed many participants that there was something that they could do to help, and as such it helped them to regain their power over the illness. For example, one individual said,

> Although I know that I may not be better than what I am now, and I could be worse than what I am now in the future. But at least if you have that reference and skill to deal with it you become less angry and less fearful of being disabled for your whole life. You become able to try things rather than just stuck sitting in a corner saying ok, that is it, I have fibromyalgia and this is it.

Another participant commented,

> I think no matter what people have they should be educated about it. Because then they can understand better why they are taking certain things or why they are limited in certain ways or why their doctor is suggesting certain medications or something. They might not get depressed about things as much, I think it is very important.

Within this group many had already made the emotional transition from feelings such as fear and denial to acceptance before the course. One such individual describes the changes she had to make in her life as a result of being diagnosed with arthritis. She said,

> When this happened it changed everything, actually I guess it changed me. I had to get control of my life. And like my mother couldn't help me with this, she can't be here all the time to lift things for me. I realized I have my life and I

> have to take care of me, that was the thing, I had to look at the disease and I had to start taking care of myself.

Another individual describes her experience when she accepted her illness: " I got back to who I was again, and then I was able to do something about it. To start to manage it from a more positive place."

Some participants felt education and in this case the ASMP, was the catalyst that helped them to make the emotional transition. One participant commented, "So it [the course] kind of eases your mind and takes the fear away because you know what you have." Another individual said, "And remember, I told you before the course I was angry and then I started to face it and accept that I have this illness but at least it is not worse and I can do something." Similarly, another individual described,

> I was very afraid at first. Of what it was, or how it would progress and all that, but now I realize you can have control over it and just to deal with it daily and do what you can do. I notice a lot of people in the course said that too. It helped to take away their fear and they felt more in charge and that they were capable of doing something about it rather than just take it easy and be afraid to do something about it.

Another individual who seemed to make the transition during the course describes her path to acceptance:

> At first I was angry and I said, why me, and then gradually I have learned to accept it and now knowing that I am not the only one, and that I am not as bad

> as the other person. And so with my limitations, I still feel I am better than others who are in worse condition and I just am doing the best that I can.

When asked if this particular individual would have made a similar transition independently without participating in the course, she responded,

> Yes, probably over time I would have been able to, but it would have probably been much later. Now that I have attended this, it has sort of opened my eyes and you know discussing with everyone and listening to other people, and their symptoms and how they manage their problems.

This quote suggests that individuals with a self-directed personality may develop self-management strategies independently. Although this may occur, it may be costly in terms of time and cost to the individual and the health care system. This quote further illustrates the concept of a self-management personality or outlook and the importance of early access to self-management health education programs as discussed earlier in this chapter.

One individual in the group seemed to remain in a state of emotional turmoil, and up to the time of the interview had not made the emotional transition to acceptance. She describes her position:

> When I was first diagnosed I was in a lot of pain and it was very difficult. I was young and I didn't know what was happening. You know, I didn't know what was going on and so I was really afraid. And then I guess, well right now I am going through a similar thing and it is like when is it going to stop, what is going to happen, what quality of life do I have and do I want to live like that?

She further indicated she is trying to make the transition. For example, later in the interview she said,

> Actually there is a group, a chronic illness group therapy that I would like to go to. I am hoping it might give the extra support. I think when you are sick though you need to have other people around who understand what you're going through.

As reported earlier, this quote illustrates the importance of support in acceptance of chronic arthritis. The individual quoted is again the same participant who had low levels of self-efficacy with the objective tests and poor outcomes described subjectively. These findings suggest that an individual's emotional state and feelings about a chronic illness may be another factor that influences outcomes. In short, poor outcomes and ability to self-manage may be a result of feelings such as fear and denial and lack of acceptance of the illness. Similarly, as described in earlier sections, an individual may not choose to participate in a program due to emotions or feelings linked to the illness. In this sense, nonacceptance of an illness may prevent an individual from learning self-management, either by lack of participation or blockage of their ability to learn self-management despite efforts put forth in the course.

Despite the low levels of self-efficacy and poor outcomes suggested by one participant in the study, the course may have helped the participant to deal with a portion of the negative emotions associated with the disease. In other words, the course may have helped her to start to accept her illness and let go of some of the fear and denial. Furthermore, the program may have helped to give her the confidence to

participate in other experiences that may give her the support needed to make the transition to acceptance and subsequently self-manage her arthritis.

Many individuals who do choose to participate in programs may be individuals who have low baseline levels of self-efficacy but are ready to make the transition to acceptance. For example, in this study two individuals made the transition from low to high levels of self-efficacy to self-manage their arthritis. Furthermore, they reported a similar transition from fear to acceptance and believed that education helped them in making this transition. Low levels of confidence may be associated with emotions such as fear, and high levels of confidence may be associated with acceptance of the illness.

Learning Self-Management

Another theme that emerged from the qualitative data was the process of learning self-management. Participants discussed a variety of factors that seemed to help them to learn to self-manage their arthritic condition. All participants interviewed indicated that they liked learning together as a group. Group interaction, which is one of the learning processes built into the ASMP curriculum, allowed for discussion, group support, sharing, and problem solving. One participant suggested that the support that she got from the group was very helpful. She said,

> I think it is good because you can identify with other people's feelings and then you don't just think it is you. You realize other people are feeling this way too. So it helps.

Similarly, another individual said,

> And to talk about it, I think that was good. And, umm, that whole counsel each other approach I really liked. What else, I like the group stuff, I like the problem solving, because my big thing is management. So I think when you have a problem, instead of sitting there and thinking what to do... I go down to the front-line people and I ask them. We've got a problem here, I am thinking this, what do you think of this or that. Because I figure, they do it every day, they have got the answers.

Another participant stated, "It is like having more contact with other people, makes you more confident that you are on the right track." Similarly, another individual commented,

> The discussion was great because you can disagree with someone and discuss your points of view so that you see all sides of the problem. Like you see it through another person's eyes. It is good.

Another participant described,

> Because everyone has their chance to talk and everyone can tell their little story to tell what they are doing to help themselves. And that is important, very important.

Participants found that the group interaction and discussion helped them to learn from each other, which many individuals saw as an important concept when trying to learn self-management. For example, one individual said that one of the

reasons she took the program was she felt she could benefit from learning from others. She said,

> I wanted to learn how to self-manage my pain, to see what I can do for myself and help me to reduce the pain I am undergoing. I heard that you can also learn from listening to others. Like what their experiences are and what helped them.

Another participant thought the discussion and group learning was helpful, she said, "Everyone liked to hear what the other fellow was doing and then they were able to compare it to their own lives and they get ideas." Similarly, when asked what helped you to learn to self-manage your arthritis, one individual said, "I think hearing what everyone else had to say, how they were managing and everyone had their own way of dealing with it. Which you learn from, you know. Yes that was good." It seemed that the course participants found it best to learn from other people who have experienced living with arthritis. Furthermore, they found the more they could relate to another person, the more they seemed to learn. One individual commented, "I know how to manage myself, but I feel that it always pays to listen to others because there are things that you can learn you know. Especially if they suffer from the same thing that you have." It was as if they learned because they could relate to others going through the same thing and they saw this as supportive. One individual said,

> Now I know that I am not the only one suffering from arthritis. Discussions with the other participants and Ellen were very helpful, there were things I

> picked up from these discussion that helped me to start managing my condition better.

One participant commented on the benefits of learning from others. She said, "The discussion is good because that is when you really hear how people cope with things and how people are dealing with things. And nobody knows better than the people who are dealing with things." Another participant said, "I think that is it, knowing the things that I could do and seeing the people and listening to the people, learning by example, the group interaction."

Another point of interest that emerged from the data was that many participants felt that learning with others helped them to maintain a positive outlook, which in turn promoted self-management behavior. Most participants suggested that being in the course with others showed them that their condition could have been much worse. For example, one participant said, "I liked to know that there are an awful lot of other people out there; you know, it sort of makes it a lot easier to deal with. And you realize that this is ok." In addition, many participants felt that knowing that they are not alone and that others are living with the condition as well helped. One individual commented,

> My attitude towards my illness has changed a lot. You know sort of, I am more positive about things now than I was before. I have seen that there are other people there who are battling the same sorts of things.

Furthermore, it seemed to help individuals cope with their condition; one individual said,

> And now knowing that I am not the only one, and that I am not as bad as the other person. And so even with my limitations, I still feel I am better than others who are in a worse condition and I just am doing the best I can.

All participants commented on the importance of a comfortable atmosphere in learning self-management strategies in health education programs. One individual said when discussing the course with the interviewer,

> I really liked the course, it was so informal and it was great to sort of talk with everyone, you can ask anything and people, someone would volunteer this or that. It was just really helpful. And I like the setting, being informal and all that, like being able to discuss with others.

Most participants interviewed suggested the importance of the lay instructor and how much it helped them in their learning the self-management approach. Most individuals interviewed reported that the instructors who had arthritis helped them to relate better and therefore enhanced their learning. They said it helped because she could speak from experience and she had the ability to put herself in the learners' situation. For example, one individual said, "Ellen put herself in our shoes, which I liked very much. And she put everything on a very logical human basis." Another participant commented,

> She is someone who knows what she is talking about. She knows where you are and what might help you to help yourself or to manage better... It is really good, I think the best teachers for situations like this are persons who are there, really there.

Another participant stated, "Yes I think people are more open and they can identify with the instructor and some of their feelings and what she has gone through, that is good."

Similarly, one participant explained when asked her viewpoint on lay instructors teaching the course,

> I thought it was great! First of all the instructor has had the experience and has been through a lot to get to there and is sensitive to anything about the subject. Whereas some types of people who don't have personal knowledge of things tend to, umm, preach and they know better and they can fall into the doctor syndrome. And I think it is wonderful! You really get the feeling that she is one of us, that she is learning too. And she has sympathy for all of this and she can talk about how it has affected her. And in the room there will be someone who has been afflicted with the same kind of arthritis that she has and it really forms a bond, a real bond. And that is great.

Many felt that the lay instructor was helpful as she was in a sense learning with the group. One participant said, "It is like she is still learning and we are helping her too, it is a real exchange. It is really good." As well, many individuals commented that the instructor spoke in a way that everyone could understand. For example, when asked if it would have been better to have a professional teach the course one individual said,

> No. These people can't, because a rheumatologist and doctors talk at this level. These people are at this level. Ellen talks at this level and she gives us

> information at this level so you couldn't have professionals, it would not be good.

As expressed in this quote, most participants felt that professional instructors are not as helpful because they can't relate to the person with the illness. Some individuals actually indicated that they felt they could learn more from their peers than they could from a health care professional. For instance, one participant described her experiences: "I have found that you learn more from the other people who have it [the illness] than the doctors. Because they are living with it and the doctor just looks at the tests."

Despite the strong belief among participants that lay instructors are more helpful than professional instructors, two individuals in the group saw the importance of medically trained instructors. One individual saw the importance of both lay and medically trained instructors. She described two different forms of health education: one with the focus on giving high-level information and the second focusing on the importance of process. She felt she had a need for both types of education. She said that the courses that would give her the high-level information that she desired required medically trained individuals to teach them. Conversely, she said the process-oriented courses required more of a facilitator who was a lay person with arthritis. Another individual explained,

> I think people are more interested in I have got this what can I do about it. The other stuff you can read in a book, you don't need a facilitator to tell you stuff that is in a book. And I think what the people really want is a facilitator

> to have a group to talk about it. You know I found this, and it did or did not work... more the social support than that kind of book knowledge.

These thoughts were consistent with those of others in the group who saw the importance of both education to increase one's knowledge of the disease and education which is process focused.

However, a second individual in the group suggested that all health education should be taught by medically trained professionals. She suggested that she would have learned more from a professional instructor. She said,

> I think it would have been a lot better, having an expert in the field teaching... you have different speakers, a nutritionist, pharmacist or even a physiotherapist, a nurse, or doctor, if you could find someone to come in and answer questions.

She commented that she had taken a health education program in the past, which was an inpatient program at a hospital, taught by health care professionals. She described the experience:

> Yes it was helpful, you know you were there, you couldn't leave, and you had, you know they did a lot, like every day you were in the pool and the physiotherapy and occupational therapy, the nutrition was there I think, I don't remember. And you know there were classes and this that and the other thing, and that was helpful.

It seemed that this participant felt that the medically trained instructors would have helped her to be motivated to self-manage. She said, "Maybe they would have

helped me do it." Although these beliefs were not the norm of the group, they have been reported. Interestingly this particular participant is again the same individual with low self-efficacy scores and poor subjective course outcomes. In this case, it seems that individuals with low self-efficacy are looking for things that are external to themselves that they believe are more able to motivate or help them. This thought will be discussed further in later sections of this chapter.

Another learning strategy that most of the group felt was very helpful to them in learning self-management strategies was the process of contracting. Participants felt that the process of contracting helped to motivate them. When asked what helped her the most, one participant said,

> Well, the contracting. When I first heard about it, I thought what the hell? I thought she was kidding at first. But umm, like I actually think it was kind of good... I think it was a good process to go through.

Similarly, when asked about the contracting process another individual said,

> Oh yes, it was very good, I liked it because it gave me the motivation to do the things I needed to do... It is because you are answerable to yourself, and you can say, did I do it? I really found it good. It really helped me to do the management things.

Another participant described:

> Well, because you had to stop and think about what you were going to do, right away. Not 2 months from now or anything, and it was only a week long and well you know you could keep it in the forefront of your mind. And you

knew if you weren't doing this you'd think, oh I should be doing this, how many more days do I have left? So it was very manageable.

One individual said, "I think the contracting was the best one for me... I used the contracting to help me try things, so it helped me to try everything and give it a chance."

Three individuals in the group stated that they did not find the contracting helpful in learning self-management strategies. Two of the participants felt that it was an unnecessary process. They said that if you need to do something you just do it. It seemed that they did not need to go through the process of contracting to motivate them to follow through with self-management strategies. For example, one individual said, "It is sort of like a childish thing. What a teacher in a public school would do sort of thing, kind of like if people are getting something out of the program they will be motivated to try it enough by themselves." Similarly, when asked if she liked the contracting part of the course another participant said, "No, because I have been doing that my whole life, it was not new. Contracting with yourself? Well when you have something to do you just do it. You don't make contracts you just do it, end of story."

The other participant who had poor course outcomes and low levels of self-efficacy described not finding the contracting process helpful but for very different reasons than what has just been described. Contrary to the other participants, this individual felt that it just didn't help her; she felt it didn't make her follow through. She just did not find it motivating for unknown reasons. She explains:

> Yea, the contracting was interesting. I think it was a good idea, I just had this problem with following through with the things I was supposed to do. I thought, there has to be something, I'm just not sure what, somehow there has to be a way of, you know, following through. I just don't know how you do it. But I would find that I would get busy and I wouldn't do what I was supposed to do. You know I just wouldn't feel like it, but you know that certain things are good for you . You should be doing them but... I just don't want to do them. I need to have someone to come here every day and make me do them, it would be helpful. Like I need a personal trainer.

Again, this was the particular individual who scored low levels of self-efficacy after the course and reported poor course outcomes. It seems that she was not motivated to self-manage, and contracting, contrary to the others in the group, was not enough to increase her level of motivation. As such, it may be that the learning style of someone who doesn't work well with a self-management approach relies on assistance that is external to themselves to learn self-management strategies. This will be discussed later in this chapter under the heading Profile of the Self-Manager.

Beliefs About the Health Care System and the Medical Profession

One of the themes that emerged from the qualitative data is described as beliefs about the health care system and the medical profession. Under this heading a variety of beliefs about the problems of the health care system and the medical profession are presented. In addition, solutions to the problems according to the study participants

are suggested. It should be noted that the term doctor is used frequently and interchangeably for the term health care professional. For this section of the paper, these terms remain synonymous in order to remain consistent with the language used by the participants of the study. It is felt that participants chose to use their doctors as examples of health care professionals due to their familiarity with them. Despite this, the findings presented are not exclusive of other health care professionals working within the health care industry as described in the definition of terms section of this paper.

Problems identified by participants. First, all individuals interviewed felt that time was a large problem in their relationships with the health care professionals that they had consulted. Many individuals stated there was no time to talk due to the health care professionals' busy schedule. For example, one participant commented, "Well, time is pretty limited with doctors so they really can't talk to you for very long and that is bad, that is really very bad." Similarly, many indicated that they feel rushed when they go to see their health care professional. One participant said, "She is so busy, and she doesn't have the time to sit down with me for an hour, you know. A lot of the time I see her she is looking at the clock when she is speaking." Another participant said, "Yea, sometimes I feel like I am rushed through, and I leave there thinking, like I have a whole load of questions and I don't really feel very good about the whole thing." Similarly, one individual discusses the importance of her doctor spending adequate time with her: "With my new doctor, she is terrific. She wants you

to see her if there is anything; she cares, really about the person. She is a doctor who arranges to have 45-minute sessions if she feels that it is necessary."

Study participants had strong beliefs regarding how medical professionals view their patients. Many participants suggested that they felt their doctors viewed them as a nuisance or as a complainer. One individual said, "In his mind I'm a nuisance, I am a complainer." Many individuals stated that they had a hard time getting diagnosed with arthritis, as many health care professionals did not believe their symptoms. One individual said, "I was sick for about 2 or 3 years before I got diagnosed and I got into that feeling sorry for myself. I did go to the doctor a few times but they told me there was nothing wrong with me." Similarly, another individual said,

> Because at one point I started to believe my doctor, that it was all in my head because... I was working then and, umm, you know the thing that they just want to... umm you know think that you are a malingerer. Like you don't want to go to work and things like that. So there were days when I would think the doctor is right, I am just too tired or but no, there is pain there. It really is pain.

This quote is related to the earlier section of this chapter that describes the emotional connection to adoption of the self-management approach. In this sense, lack of diagnosis can promote denial and nonacceptance of the illness, which as presented earlier does not allow for successful self-management of the chronic illness.

Many participants suggested that they felt that many health care professionals do not accept their patient's descriptions of their symptoms and in some cases do not

accept the diagnosis of an illness. For example, one participant commented, "Fibromyalgia is still really not very well accepted by doctors." One individual explained that this might be one of the reasons why individuals do not participate in education programs or want to talk about their illness as they have been discredited by the medical profession. When commenting on an acquaintance with a chronic fibromyalgia she said,

> For a long time I heard it not just from her but from other people, that it was all just in your head, that it was imagined. That the fatigue was nothing more than just depression, that it was all kinds of things. And I think that people perhaps who have it and have had it for a long time, almost are afraid to talk about it because they think that other people are going to think that there is just sort of thing, there is just a mental problem that they had, or they feel sorry for themselves, so I think that with fibromyalgia, that that is the case.

Another individual describes the frustration she felt when she had difficulty being diagnosed with her chronic illness. She explained,

> I was annoyed enough at my doctor to learn and do it myself because they, not on purpose, had put me through months of hell because they were telling me that it was not this or not that, go here, go there, you know, and I am telling them I think it is this and they are telling me it isn't.

In this particular case, lack of diagnosis and belief on the part of the doctor was the impetus that caused that patient to take the matter into her own hands. This is an

example of neglect on the part of a health care professional promoting self-management behavior in a patient with chronic disease.

From the patients' perspective, study participants seemed to have strong viewpoints on the health care system and the medical profession. Many participants felt that some medical professionals tended to treat their patients' health problems symptomatically, using medications. From their experience, they believed that some doctors feel that medication is the answer to all their patients' problems. For example, when talking about the treatment given for her fibromyalgia one individual said, "He just kept giving me medication for my pain. He just gave symptomatic treatment and told me it was all in my head." Similarly, another participant said that she had actually changed doctors as she felt her doctor had been overmedicating her. She said,

> It was after my husband died that I changed doctors. And the main reason was that the doctor who I had for 35 years was handing me drugs to help me overcome my grief, and I was spaced out. It was terrible... I started to notice he was becoming more and more dependent on solving things with drugs. And I felt sometimes, I mean I don't like taking pills... But it really came to a head when my husband died and, umm, his way of treating that was to hand over drugs. And he seemed to see that as a panacea.

All participants who had had an experience similar to this had since changed doctors. Again, this is another example of actions and judgment that were made by a medical professional that, although they were at one time distressing to the patient, have helped individuals to begin to self-manage their health and health care.

Many individuals in the study group suggested that they felt medical professionals who in the past were viewed to be on a pedestal should change their professional approach and image. They suggested that the traditional ways of thinking about medical professionals is no longer suitable in today's society. When discussing the traditional role of medical professionals, one participant said, "That has gone out with the horse and buggy, doctors are not Jesus anymore, God anymore. They are just normal people who happen to be knowledgeable." Later in the interview she explained,

> That is the way doctors were, they would say ABC and take this and that-and that always worked up until this generation where people suddenly are more informed-through the Internet, through education, through television, and it is not working as well as it used to.

This quote illustrates the frustration among participants of what was labeled as the traditional medical model in the introductory chapter of this paper. Despite some of the viewpoints surrounding the problems of the current health care system, individuals interviewed discussed their ideas of how to improve the system. Themes from their insights are discussed herein.

Solutions to the problems. Individuals interviewed felt that most of the solutions to their problems with the health care system and the medical profession could be resolved with a change in the patient-provider relationship. Individuals interviewed described the ideal relationship between a health care professional and a patient.

All participants indicated that good communication skills were essential. Specifically, many individuals felt that good listening skills were very important. One participant said,

> You must be able to be open with your doctor... your doctor is a good listener and really listens to how you really feel. A supportive doctor is important. A doctor who supports you and will work with you to find answers to problems. Let's try to find out what the real problem is. Like a real partnership.

Many individuals interviewed described past experiences with the medical profession where listening and communication skills were very poor. One individual said,

> I felt like they are not listening, but if you keep on going you get frustrated when the answers don't change. Especially for me, because I am not a pill person and when the answer was always it is in your head so here is a pill, you search for something else.

Individuals indicated that this type of interaction with health care professionals caused them significant frustration. Again, as presented earlier in this chapter, lack of communication skills can result in nonacceptance by the health care provider and therefore the patient. Again, nonacceptance in this case of chronic illness breeds lack of adoption of self-management behavior and increased reliance on the health care system for answers.

Many individuals in the group indicated that a partnership between the patient and the health care provider was important. They said the relationship must be built upon a level playing field with mutual decision making. As one individual

commented, "Everyone is actually on an 'even steven keel'. And the patient doctor relationship is also on an even keel. Equal people." The specific roles of the patient and the medical professional in this relationship were described and are reported herein.

Individuals who were successful self-managers (i.e., positive course outcomes) suggested that the health care professional's role in their health care was small. They described it as more of a consulting role. They indicated that medical professionals have little responsibility in managing one's health care. They described the role of the medical professional as diagnostic rather than treatment focused. Furthermore, they suggested that health care professionals are important for referrals to other health care professionals and prescription of medications when needed. For example, one individual said,

> Umm, I would say that it is 90% of it is my responsibility or more, because the doctor is there to provide you with information, but a doctor has to provide information on every ailment that is going and so they can't take responsibility for you doing it. They can tell you what the problems are, they can give you the tests or direct you to them, but they can't take responsibility beyond telling you what might work. It is me, I have to do it.

When asked, "How large a role does your doctor play in helping you manage your arthritis?" one individual commented,

> No, not anymore, no not at all, she was just there to help find out what was wrong. If I had another problem I would go back to her, but no she really has little to do with the treatment.

Another participant said,

> I don't know, I think fairly large. I am still relying on him with my medications and to know how I am doing, but I guess the rest is mine, the management part is my side.

Similarly, many felt that seeking help from a medical professional was used only as a last resort. They indicated they would only visit their health care professional if they had a problem that they could not solve themselves. For example, one participant commented, "Just really if I have a problem, if I thought I was on the wrong track, if I thought something wasn't working." Another individual said, "Well, I think for things that I feel I can't cope with that I would turn to the doctor. But what I feel I can cope with, I cope with."

Most individuals felt that the health care professional's role should be more that of an educator. Furthermore, individuals felt that they did not get enough information from their doctors, and although they understand the limitation of time, they saw this as an important part of their health care. They felt they needed more information to help manage their condition. One individual commented, "There should be more education, and if doctors can't do it, maybe nurses could. Because I think people want to be educated and they want to learn and know." Another participant commented,

> I don't know, communication is really the key, but the way the health care system is, it is not really set up that way. But I guess we just have to find a new way of doing things, we have to realize that we can only educate so many doctors and have so many specialists out there. And maybe they don't want to spend all their time counseling. So maybe, we ought to get more people like my nurse practitioner who have good medical knowledge and can spend time. So I think we have to look at new ways of doing things.

Another individual commented,

> I think there could be just having more time for questions, and talking more about the future and what to expect and how the disease is going. Like how do I compare to the last time, you know I want to see all the test results and x-rays and talking about how the disease is going. You know they really don't tell you. They just don't. Like I know how I feel but there is a lot of information like x-rays and tests and all that, and they don't share with you the details of the disease. Like I am always asking, well how does it compare to last time, you know, I want to see all the charts and everything. I think more information would help me manage better.

Again, as described earlier in the chapter, the importance of open communication in the form of discussion was highly valued among participants. Participants felt that discussion with their doctor was a form of support. Similarly, individuals believed that discussion, support, and education in general helped them to bridge to acceptance of the illness, which helped them to self-manage. This mirrors

the emotional transition described earlier as a result of the support gained from the ASMP.

Most individuals described their role as a patient as active rather than passive. One individual commented,

> It is important that the patient knows what is going on... because then they can sort of steer the doctor because they know that they can say to the doctor, I know this or I have tried this and what do you think. Whereas the other way around, the doctor is leading you and you are the one that has to live with it.

Successful self-managers felt that they were responsible for their health care and well-being. For example, one participant said, "Like if it is a partnership, then if I don't do my part then it doesn't work." Participants indicated that they did not feel they needed a lot of help from the medical profession in the treatment of their arthritis. One participant said when asked about the patient and doctor roles, "Well, not much, you are the primary person, the doctor is there to start you off and the patient should consult with him as needed." Similarly, another participant said, "There is nothing they can do about it, but there is something you can do about it. You can do something about it yourself, the doctor can't hold your hand and walk with you."

Participants suggested the importance of knowledge before seeing the doctor. In this sense they suggested that being educated about their condition before seeing the doctor was helpful. One individual said, "Well, from my experience, I found that the more the patients know the smarter the doctor is." Similarly, participants commented

on the importance of knowing how to approach and talk to the health care professional. One individual commented,

> Well, I found that if I know enough information, I know what to say to them and you know, if she says something, you know I can sort of relate to that... I can relate it to when I had the thyroid problems because I didn't know how to talk the doctor.

One individual interviewed had some strikingly different beliefs regarding the medical profession and her role in the treatment of her arthritis. Again, this was the same individual who had low self-efficacy scores and poor course outcomes and described herself at the time of the interview as unsuccessful at self-managing her arthritis. Different from the rest of the group, this participant indicated that she needed a lot of help from her medical professionals in the treatment of her arthritis. She said this has especially been the case as she feels her condition is worsening. For example, when asked, "How large a role do health care professionals play in helping you to manage your arthritis?" she responded, "Larger and larger all the time. Because I am needing more and more help as my condition gets worse." This individual seemed to have a heavy reliance on her doctor, yet never seemed to get her needs met. She commented,

> I have a rheumatologist who is pretty good but he is very busy. He's too busy; he needs to clone himself. And he is very difficult to get a hold of by phone. I call and I want to say can you please talk to me about this and tell me it is going to be ok.

Similar to the rest of the subjects, this individual stated that she did not believe in taking medications for the long term. When asked why she did not like taking medications long term she said, "It is just unnatural, you know it is just not natural to take chemicals all your life. There has to be something. Like there had to be something that started the arthritis so there must be something to stop it." The quote suggests that this particular individual tends to be cure focused in her approach to arthritis treatment. This point will be discussed in further detail in the section Profile of the Self-Manager later in this chapter.

Despite her beliefs about medications, this particular individual stated that her next step or long-term goal in treating her arthritis was to participate in a drug study. When asked about the drug study she said, "It is a medication study that my rheumatologist wants me to participate in. I have to do something because it is not getting better. It is getting worse, and so I guess I will have to revert to some sort of drug." She added further, "I don't like pharmaceuticals, so I am having a hard time with it." The feeling that the researcher received throughout the interview with this individual was that she had given up and as such felt forced to forfeit her personal beliefs to those of her doctor, whom she was becoming more and more dependent upon, and due to the control the arthritis had over her life. Furthermore, she had not accepted the disease and was looking for things that were external to herself to control the illness as she did not feel capable to do so herself. Again, this point will be revisited in detail in the next section of this chapter, Profile of the Self-Manager

Profile of the Self-Manager

Results of the interviews with participants revealed an enormous amount of information about the concept of self-management and the self-management approach to health education. A large theme that emerged from the data was labeled Profile of a Self-Manager. This section of the chapter describes the beliefs and traits of individuals who felt that they were successful in using the self-management approach in living with chronic arthritis. In addition, traits of individuals who are potentially not successful in adopting the self-management approach were also revealed and are reported.

The successful self-manager. Successful self-managers believed it is necessary to be disciplined and motivated to manage their arthritic conditions. For example, one self-manager said, "I have the motivation, so it works for me."

Self-managers tended to have a positive outlook on life. As explained by one participant, "I feel, I guess, that a lot of things happen as you get older. I look on the bright side of things." Another individual discusses the importance of having a positive outlook:

> I see it as being sort of an optimist or pessimist. And you have to have a good outlook on life, because I realize how important that is with my disease. Like if I get a run in my nylons, I can let it ruin my day or I can say what am I going to do about it and go buy a pair. And move on.

One individual described the attitude needed to self-manage successfully, she said,

> Some people are very negative. It is like a mental attitude. I think a lot of people being able to cope with something is their own attitude. If you have a defeatist attitude then you might just sit down and say let it take over. Whereas if you have an attitude like, I can manage this, I can do something about this, it could make a difference.

When confronted with an illness, self-managers believed there was something they could do to help. Their focus tended to be on their abilities rather than on their limitations. When describing why self-management helps her, one participant said, "It helps me to focus my mind and my energy. It helps me to focus on what I can do instead of focusing on my limitations. So I focus on what I can still do. And hey I am good at doing this or that." Later in the interview, she went on to say, "Well I know I am different now, I cannot do things that I want to do at the pace that I want to do it, but as I said, I just do the things as I can. Just do what I can manage to do."

Most successful self-managers felt that their arthritis was not a limitation; that it was a bit of a nuisance, but it was manageable. They had the belief that there are always options in life. Successful self-managers described themselves as people who wanted the most out of their lives and were not going to let the illness stop them. They did not see having the illness as a big deal, and they felt that it did not make them stop them from doing things or stop living. For example, one individual said,

> It hasn't stopped me from doing things, I just don't do as much anymore. I can still travel, but I am sure I will just have to make adjustments, like get up every

> hour while I am on the plane and things like that. You can still do things, but you just have to manage your time and your energy a little bit differently.

Another individual describes how her arthritis does not hold her back from experiencing things in life. She said,

> I think when you get sick or have such an experience, you have a whole new outlook on life. So you get very appreciative, I am not saying I wasn't appreciative before, but I definitely do things for now and not tomorrow. So if we are thinking about doing something and oh, we don't have the money or we don't have this or that, I say you know what, let's go now. Because I think tomorrow I might not feel this good, so lets go now.

Similarly, one individual described how the course changed her outlook: "The course has shown me that you can work your way through this. And have a full life and keep doing the things you want to do and maybe even do more."

Other self-managers interviewed described arthritis as a limitation, but as controllable, and they just had to do things a little differently. In this sense, they said having arthritis is a lifestyle change. One individual said, "I see it as a bit of a limitation, but I love to ski and bike and I do. So I do all the things I really like to do. So it is not holding me back, I just choose things I like to do and do them." They noted the importance of accepting that things were different now. In addition, those who saw having arthritis as a limitation felt that education could help them overcome many of the limitations that arthritis brought to their lives. Most commented that the ASMP helped to do this.

Self-managers interviewed tended to be self-directed individuals who enjoy learning. They are information seekers and naturally have a certain "need to know" and interest in reaching out to find answers. For example, one person said, "When I was diagnosed with it [the arthritis] I decided to read more and find out more of what I can do." When asked how she heard about the program, one individual answered, "I heard about it really by investigating, phoning the Arthritis Society. I am the kind of person that when I discover that I have got something wrong, I want to know what it is and what is available." Another individual stated, "Well I am the eternal student, I love to learn , it is just part of who I am, it is my nature."

Self-managers described the importance of taking an active approach in the treatment of their condition. One individual described:

> When I was diagnosed I just couldn't get it fast enough, you know, just the not knowing drove me nuts. I don't know, I just think some people think that if they don't think about it and don't deal with it will just go away. You know problems don't go away if you just ignore them. And, umm, they just don't talk about it. I don't know, I am not really that type of person.

Self-managers are independent; they tend to like to do things for themselves. As one individual stated when asked why she chose to self-manage, "I am an independent person and I want to stay that way." Later in the interview she continued, "I am an independent person and I like to be in control of my life. I really do, I don't like handing it over to other people." Similarly, another individual described:

> I am a very independent person, I am reluctant to get help, if I can do something for myself I'd much rather it, unless I really need help I don't ask for it. Only if I absolutely need it do I ask. So learning all these strategies to self-manage is gearing me so that I can help myself and I can attain my goals. With all the ideas and tips and strategies it is helping me to be independent, which is what I like.

Successful self-managers in the group tended to have a take-charge personality and when faced with obstacles, were individuals who found ways to help themselves. As one individual answered when asked when she learned how to self-manage,

> I learned it I guess when I left Canada and went to France. And I got there and I thought help! Here I am in a foreign country and I had to learn how to cope with life. If there was a challenge, I learned that you have to solve your problems, and if you can't do it yourself, you have to get help, you have to get information. You know you have to deal with it.

From the data collected, it seems good self-managers see themselves as having the ability to manage problems they face. For example, one individual expressed, "I think that I have this outlook that when I am faced with a problem I really say, how can I help myself? Instead of people who have the attitude of trying is no use." Similarly, another participant commented, "I am an information type of person and so if there is a problem I can solve it. That is what I do all day in my job, is solve problems. If there is a problem, give me the stuff and I will solve it, I will find a way."

Successful self-managers have the ability to adjust to change easily. For example, when asked how has arthritis changed your life, one individual said, "It hasn't stopped me from doing things, I just don't do as much anymore. I do a few things less." Similarly, another individual commented, "I like to exercise a lot and that changed things. So now I have just changed the way I exercise. I had to adjust to it. No more aerobics, now walking and stretching and strengthening. And I am enjoying it."

All the self-managers interviewed believed that it is important to care for oneself and that each individual is responsible for their own health and well-being. One individual commented, "You have to be very self-educating with everything, because if you don't nobody else will do it for you. You have to take responsibility. You have to accept responsibility for yourself." Another individual commented, "The self-management approach works well only with somebody who is accepting responsibility for their own actions."

In this sense, individuals who were successful self-managers felt that they were well suited to the self-management approach as it allowed them to take responsibility for themselves. In addition, they felt no one could manage their health like they could. One individual said, "Yes, I think self-management is a very good approach because we are all responsible for ourselves and nobody else can really manage our lives like we can; we all know ourselves."

All successful self-managers interviewed discussed the need to have some control over their life. One individual stated, "Well, I like to be in control, personally,

and that is why I like to inform myself of what is wrong with me and how I can treat it." Another individual who was successful at self-managing her arthritis commented, "It worked well because I like to have a bit of say in what is happening. Because people can say take this and take that and then you can say, well maybe I don't have to take that. This is the best thing because you can find where you are comfortable and what is best for you as a person." Another individual commented, "Self-management helps me gain more control. I still have a hard time with some things, but really it is under control. But I don't know what the future will bring. But I just try to do my best. That is what I can do."

All individuals saw education as one of the most important components of managing their health care. One individual said,

> I think patients need education and I think more and more people are getting educated. Like now you go to a pharmacy and there is all sorts of information. And so I think the doctor should have something like that. Some sort of sheet or something so you can get some good information and it describes what you can do about it, and how you can help yourself a little bit more.

Another individual expressed,

> I think health education is important because it brings knowledge. Knowledge of what is really happening, especially for people who don't have health background. Like if they know what is exactly going on inside of their body, they will know what they can do and they will be more accepting of their

> limitations and they will be able to cope more and be able to deal with it without being angry.

Self-managers interviewed felt that health education is important as it helps them to handle their arthritis. For example, one individual said, "I think in order for me to manage my disease I have to understand it. That is the key, I have to be able to, like I have to be in control. So if I have the knowledge you know I can be in control." This quote illustrates the fact that education can help patients to control certain aspects of the illness, which is what self-managers are looking for, increased control. Another individual said, "I think educating yourself about any health problems you have is an important part of helping yourself and being responsible for yourself." Again, the importance of self-responsibility is evident through this quote. Self-managers felt that education is important because it gives knowledge, and as one individual said, "knowledge is power." One individual described the importance of education. She said,

> It is like learning how to drive a car. I don't think you could sit down in front of the steering wheel and pedals and drive one. You have to be taught how, you have to be instructed, you have to have experience, and otherwise you are going to kill yourself. And I think that is true of anything that is an obstacle, and then you can handle it and use it to your advantage.

Individuals seemed to feel that knowledge helped them to gain some control over the disease and gain acceptance of the disease, which is power.

Self-managers tended to be of the belief that process rather than content oriented education is critical to learning self-management. In addition, they indicated that educational processes that were group focused were most helpful in learning self-management. These points have been discussed earlier in the chapter under the heading Learning Self-Management.

Individuals interviewed had an outlook that was focused more on the day-to-day management rather than waiting for the ultimate cure for the disease. For example, one individual said,

> I mean, you can not cure it, but if you can minimize the discomfort, you can do your best, you may not be able to do it 100% but at least if you have 60% then you can still use 60%.

Individuals who were successful self-managers stressed the importance of teaching others how to manage their arthritis rather than focusing on a cure. One individual commented,

> I think there should be a focus on not disregarding chronic illness because it is something that they have no cure for now, but at least alleviate the pain and symptoms that these people are feeling. Because I think that learning or teaching a patient to deal with the symptoms is more important because it is not curable. So what do you say, there is no cure for that so be it. At least if you can say yes, you have fibromyalgia and there is no cure for it now but at least you can do something to manage your pain, your fatigue, your symptoms.

Another individual commented, "As much as research is important, so is getting people through the disease, and you know you have to manage it, or else it would be a hundred times worse."

None of the participants felt that taking medications was the solution to health problems, but admitted that they could be helpful in managing symptoms from time to time. For example, one individual described a conversation with an acquaintance who depends heavily on medications:

> Actually we were having a discussion about pills and how I don't like to take pills, because she is always taking pills and I said if I took that amount of medication I would be zoned out for a week, and she said but this is the only way I can cope, I can't live without them. But if it were me I would do it differently, because I would say I will only do what I can do because I don't want to be dependent on medication.

Successful self-managers seemed to accept the uncertainty of the prognosis and had the attitude that they could only try to do their best. They saw their illness as just another thing in life to manage. One individual said, "It is just another thing, you know. It is not the focus of my life, it is just another thing to manage. It is kind of like having ingrown toenails!"

Unsuccessful self-managers. Through analyzing the qualitative data, themes arose pointing to the types of persons who tended to be unsuccessful using the self-management approach. Results indicate that individuals with low motivation and low effort to self-help are not successful self-managers. For example, one individual said, "I

think it is called self-discipline, and not everyone has self-discipline." Furthermore, individuals who lack follow-through are not successful at the self-management approach to treating their chronic disease. One individual who did not have good outcomes from the program stated,

> I think self-management is a good idea, I just had a problem with following through with the things I was suppose, to do. I thought, there has to be something, I'm just not sure what, somehow, there has to be a way of, you know, following through. I just don't know how you do it.

One individual who was a successful self-manager described,

> They [people who are not successfully self-managing] probably won't accept responsibility for themselves and for their own management, and they are not motivated to help themselves. And unless you have the motivation there is nothing, forget it, you might as well be a couch potato-sit on your couch and have arthritis and just be miserable.

Participants further suggested that individuals who lack discipline and "get-up-and- go" may also tend to have a problem adopting the self-management approach to health care. In addition, individuals interviewed thought that those with more dependent personalities might not fare well with the self-management approach. One individual suggested, "I think maybe motivation, and they are just not the type of person. They are dependent, not independent but more dependent."

Some individuals interviewed suggested that to be a successful self-manager you have to take responsibility for yourself and your actions. One participant commented,

"Individuals might not do well [with self-management] if they can't take responsibility for themselves." She continued,

> They did not want to help themselves, they feel that everything that happens to them in their lives is someone else's fault. They blame their problems on somebody else. These people will not accept responsibility for themselves and that is the key.

She added, "Then they lose out because they don't take responsibility and no one else is going to. End of story. They have to take responsibility to care for themselves."

Participants felt that individuals might not do well with self-management if they had a negative attitude. One participant explained, "A lot of people see getting older meaning getting more feeble. And not doing things and having or taking the line of least resistance. And I feel really sorry for them."

Many individuals in the group interviewed suggested that individuals who are not suited to self-management might be of the belief that they have no control over the illness or they feel that the illness is out of control. The individual who did not work well with the self-management concept indicated she hates having arthritis, as it is a limitation and even a handicap, as she can't do the things she wants to do. She stated, "I hate it. You can't do anything you use to do, your life is just different." Later in the interview she continued, "It means a lot less freedom, it dictates if you can do things, it controls your life I guess." This quote illustrates the way she saw it as controlling her life. It seems people in this mindset tend to give up personal control to

the disease. The individual in the group who did not fare well with the self-management approach commented,

> So you don't know what is going to happen next, that is the hardest part. You know, I can't even make plans for tomorrow because, and socially I just don't do anything anymore, you know I rarely, it has been such a long time since I have been out socializing because I think well, I don't want to make plans and then let someone down, because I don't know how I will feel that day. So I just don't make plans.

Furthermore, individuals felt that those who are not suited to self-management are likely to get control from external sources like medication and doctors. One individual explained, "I think having the doctor give them prescriptions helps them to feel in control, they think oh well the doctor gave me something. Then they think, I just take it and it will be all better."

Individuals suggested that taking a passive rather than an active approach to their health and health care is not suited to the self-management model. In this sense, many may take the "do nothing and it will go away" approach. Similarly, many individuals with these beliefs may have given up and stopped trying to help themselves. For example, the individual in the study who admittedly did not work well with the self-management approach said, "I just think the course gave me some strategies for trying to help with, but yea, it didn't change anything, it is still a big pain in the neck." Further, the participant said,

> I had a problem following through with things that I was suppose to do. I thought, there has to be something, I'm just not sure what, somehow there has to be a way of, you know, following through. I just don't know how you do it. I told her [the instructor] that I needed to go to into the army or something for awhile so I could get that motivation and discipline that I needed because I just have a hard time doing things.

Another individual commented,

> Giving up was not an option, those are the types of people who get into a spiral, they don't do something about it and so it gets worse and worse and then because they don't do anything about it so it gets even worse and the fear can really tense you up too, so it gets worse. You have to be brave about it and some people just aren't.

Participants suggested that individuals who are dependent upon others or medications to help them may not work well with the self-management approach. One participant offered, "Well, there are many people who like to have prescriptions. As indicated by the individual who does not consider herself a good self-manager, "I need more help from my doctor than before." It is apparent that her illness is too overwhelming for her to manage and she has a need for more support from her doctor. Again it seems that unsuccessful self-managers tend to look for external ways to help them to manage their condition.

Many in the group suggested that individuals who don't do well with self-management may be cure focused. In this sense, they feel the only hope for them is to

find a cure for the disease. One individual suggested, "Some people want the quick fix, and in this case they don't understand that there is no quick fix." They might actually see trying to self-manage as pointless. One individual who had poor outcomes from the course had no answers when asked the best way to treat her arthritis. She said, "I don't know. I just have no idea, I wish I could tell you, I wish I had the answer." This response may be the case because in her mind, if there is no cure, there is no answer. Another individual who was a successful self-manager indicated that self-management might not work well for individuals if they are cure focused. She said, "All they know is they don't like what they have, they don't know why they got it, and it is up to us to cure them or fix it."

The viewpoints of all individuals interviewed suggests that using a self-management approach is somewhat dependent on the particular individual's personality, beliefs, and attitudes. This concept is similar to that which was discussed earlier in the chapter, which explains why some have poor outcomes with self-management programs and why others just don't participate in self-management health education programs.

Summary of the Findings

Course Outcomes

The Arthritis Self-Management Program studied showed an increase in the overall self-efficacy for participants as a group. Specifically, significant increases in self-efficacy were found in two of the three subscales which comprised the total self-efficacy score.

Four participants described their course outcomes as excellent, 2 described their outcomes from the course as good, and 1 individual indicated she had poor course outcomes. Individuals with good outcomes indicated that they would have benefited more from the course only if they had taken it closer to the time of being diagnosed with chronic arthritis. The individual who had poor outcomes was unsure of why the course had been unhelpful to her and admitted that she felt she was just not a good self-manager.

Four participants scored high, and 3 participants scored low on the precourse self-efficacy scale. Postcourse 6 participants scored high self-efficacy and only 1 participant scored low self-efficacy to self-manage their arthritis. The 2 individuals whose scores changed from low to high had the most dramatic changes in self-efficacy scores.

The 6 participants with favorable outcomes all scored as having high levels of self-efficacy to self-manage their arthritis upon completion of the course. The one

individual who scored low on the self-efficacy scale both before and after the course was the individual who subjectively described her outcomes of the course as poor.

Comparison of the visual analogue scale and Lorig's self-efficacy scale pre- and postcourse suggests that individuals may be better judges of their self-efficacy to manage their arthritis upon course completion.

Possible Reasons for the Poor Outcomes of the Course

The reasons for poor course outcomes cited by participants of the study focused primarily on the notion of a self-management personality. Participants indicated that an individual's motivation, general outlook on life, attitudes, and beliefs are the primary reasons why some people are unsuccessful self-managers. For instance, individuals with low motivation, a negative outlook, and cure-focused beliefs were all examples of characteristics of poor self-managers. This point is further discussed in detail in the section titled Profile of a Self-Manager.

Reasons for Low Enrollment and Participation in Self-Management Health Education Programs

Participants suggested that individuals may not participate in self-management health education programs as they don't know how they will benefit from a program and/or they don't think the program will help. Some participants commented that some individuals do not want to be seen as sick. They said that emotions such as fear and denial are common with chronic health problems and that these emotions could

block an individual from participating in a program and in self-managing their arthritis. Further, many individuals commented that if an individual can transcend those negative emotions and participate in the program, they can have life-affirming experiences which can empower the individual to handle whatever the illness brings. Many individuals interviewed described having this experience during the course.

Personality type was another reason for lack of participation in programs. Again, as indicated in the previous section of this chapter, participants felt that individuals who inherently are not motivated or are unwilling or uninterested to learn would not participate. Furthermore, they thought that individuals who are overly dependent on medications or health care professionals would not participate.

Individual interviews suggested that lack of participation in programs may be a result of the hectic pace of life in today's society. Simply, they suggested that many individuals with chronic arthritis may just not have enough time in their life to participate. Despite this, many commented that they participated because they place a high value on their health and well-being, and as such they made time to participate in the program. As a result, many individuals interviewed thought that lack of time and the hectic pace of life was merely an excuse used by others to avoid participation.

All individuals interviewed suggested that many individuals may not be aware that health education programs are available. Many indicated that the lack of awareness is a primary reason for lack of participation in self-management health education programs. In addition, many interviewed indicated that the information age has made sources of information more readily available. As such, it was thought that

many individuals may be getting the information they require from other sources, such as the Internet.

Ideas to Increase Participation and to Improve Self-Management Health Education Programs

Many individuals indicated that there was nothing that needed to be done to improve the course. Some individuals suggested that increasing the size of the class would have allowed for increased diversity, increasing the potential for participants to relate to others in the group, and therefore learn from others in the group. As discussed in the section titled Learning Self-Management, participants stressed the importance of learning from others-especially those to whom they could relate.

All participants suggested that the program would have been better if there had been more time. Many thought that more time would have allowed for more discussion in the group, which was a highly valued aspect of the course. They felt that more time overall would have allowed them more opportunity to connect with each other and to give and receive feedback.

Most participants suggested that support after the course would have been helpful. They indicated that they would have been interested in a support or interest group and would have like to have had the opportunity to meet again as a group in the future.

Participants strongly suggested the importance of taking this type of course soon after diagnosis with the health problem. Again, individuals with only good

outcomes indicated that the program would have been more helpful to them if they had taken the course sooner after they had been diagnosed with chronic arthritis. They indicated that they had to learn how to manage their condition on their own over a long period of time. They felt that taking the program would decrease the amount of time spent getting answers from their health care professionals. They recommended that the concept of early educational intervention is critical to marketing and promotion of the program.

One individual interviewed suggested the course could have been improved if the instructors were medically trained. This thought was inconsistent with the rest of the group but was a strong belief of this particular individual, and as such, it has been included in the findings as an orphan belief. This particular individual is the same individual with low levels of pre- and postcourse self-efficacy and poor subjective course outcomes and ability to self-manage.

The Emotional Impact of Chronic Disease and Self-Management

Individuals interviewed discussed the impact of emotions when living with a chronic illness. Common emotions when first diagnosed with chronic arthritis were described as fear disappointment, confusion, uncertainty, anger, frustration, and depression. Many suggested that they had a hard time accepting their arthritis and that they had experienced times of feeling sorry for themselves. Many believed that although at one time they had felt helpless and that there was no hope, they were able to transcend through these emotions and ultimately accept their illness. Furthermore,

they believed that acceptance of the illness is essential to living successfully with the illness. Individuals in the group described the transition of going from negative emotions such as fear and denial to a more positive outlook and acceptance of the illness. All but one individual felt that they had gone through the transition from fear and denial to acceptance of the illness. This process occurred at different times and at different rates for each individual. Furthermore, they felt that support was helpful to them in going through this transition.

Many participants commented that self-management health education was a form of support. They felt that education helped them to decrease their feelings of fear, anger and depression. They thought that education helped them to accept their arthritis because it showed them that they could do something to help themselves. In addition, it showed them that others face similar problems and that their peers are often in worse condition. Many interviewed suggested that they felt the ASMP was the catalyst that helped them to transcend from fear to acceptance. Although these individuals felt that they would have been able to make the transition on their own, they felt that the course helped to speed up the process.

One individual in the group who had low levels of self-efficacy and did not have good course outcomes seemed to be stuck in feelings of fear, anger, and denial. Comments she made indicated that she had not yet accepted having arthritis. In this way, nonacceptance of the illness may not have allowed this individual to fully participate in self-management and in turn gain the confidence or self-efficacy to

manage the illness. Therefore, lack of self-efficacy to manage their arthritis may have resulted in poor outcomes.

Learning the Self-Management Approach

Study participants commented that group learning in the form of discussion, problem solving, and group support were the best ways for them to learn to self-manage their chronic arthritis. They stated that group interaction allowed them to learn from others who were going through the same thing. In addition, they believed that the more a person could relate to another person, the more learning that took place. Participants felt that learning from others helped them to have a more positive outlook, which in turn helped them to self-manage their arthritis. They said that learning from others who were worse off helped them to feel less sorry for themselves and enabled them to self-manage their condition.

Participants indicated the importance of a warm, comfortable atmosphere in health education. They indicated that a supportive atmosphere built on trust and respect was critical to learning self-management.

Many in the group felt that they could learn better from an instructor who was a lay person with arthritis. They said it helped them to learn, as the instructor was able to speak from experience, and as such they could relate to them. Furthermore, many participants saw the instructor as a colearner, which seemed to empower them to learn. Most individuals interviewed indicated that health care professionals would

not be as effective as instructors with arthritis because participants could not relate to them.

Two individuals in the group saw a role for medically trained instructors. One individual commented that for high-level information, medically trained instructors were useful, whereas for support and more process-oriented programs, lay instructors would be better. The individual with poor outcomes felt that medically trained instructors would be ideal, as she felt that they might help motivate her more than the lay instructor.

Some individuals in the group felt that contracting helped them to learn self-management strategies. They commented that the process of contracting was useful as it motivated them to perform self-management behaviors. Other individuals in the group did not find the process of contracting helpful in learning self-management. Two individuals said that they did not feel that contracting was necessary to motivate them. They seemed to think they were motivated enough internally to practise self-management and as such, they saw the task of contracting with oneself as redundant. One other individual in the group felt that contracting was not useful, as she felt it was not helpful enough to motivate her. Again, this was the same individual with poor course outcomes and low self-efficacy to self-manage her chronic arthritic condition.

Beliefs About the Health Care System and the Medical Profession

All individuals interviewed felt that a major problem with the health care system was that their health care professionals did not have enough time for them.

They felt there was no time to talk and they felt rushed during appointments. Many indicated that their doctors felt that they were a nuisance and complainers. In addition, many individuals had a hard time getting diagnosed by their doctor, as their doctor discredited them and did not believe their reported symptoms. Many participants felt that lack of acceptance on the part of their doctor caused them to have a hard time justifying their illness, which in turn kept them in a state of denial rather than acceptance. For some individuals, this nonacceptance on the part of their doctor resulted in feelings of frustration and motivated them to take increased responsibility for their health and health care.

Many individuals interviewed felt that the medical profession is medication focused, and that in some cases the discrepancy of the beliefs between the doctor and the patient initiated self-management behavior on the part of the patient. Many individuals in the past have had to take their health care in their own hands due to lack of professionalism or conflicting values between patient and provider. Although these problems caused the individual much frustration, they admitted it promoted them to take responsibility for their health and health care, which they saw as a positive thing.

Many participants felt that the role of the doctor should no longer be that of an authority figure. They commented on the importance of equality between the patient and the health care provider. Furthermore, they felt that the lack of equality was an out-of-date way to approach health and health care. Participants indicated the importance of health education in the doctor's office, but understood that professional time restraints restricted the availability.

Individuals indicated that to improve the state of their health care they needed to change the interaction with their doctors. They stated that good communications skills were essential and indicated that lack of communication leads to poor understanding, frustration, and ultimately denial of the illness. They felt that their relationship with their health care professionals should be a partnership with mutual decision making. They stated that their health care providers had a small role in treating their arthritis and that the doctor was a source for diagnosis, referrals, and prescriptions for medications, not treatment of their chronic disease. They said that they would go to see their doctor only if they needed more help and felt that they could not solve the problems they were having themselves.

Participants felt they needed more time from their doctors. They felt that more time would allow for improved communication, support, and discussion-all of which they valued and believed would promote acceptance of the illness. Furthermore, they believed that more time would allow for more education and information, which they saw as an important part of self-management.

Self-managers indicated the importance of taking an active approach in their health care. They saw their health care as their responsibility and did not want to be reliant on their health care professionals or the health care system in general.

The one individual who had poor course outcomes and low self-efficacy to self-mange admitted that she felt she was not a successful self-manager. Contrary to the rest of the group, she felt that she was needing more and more help from her doctor as time went on. She tended to rely on him and be dependent upon him to make

decisions for her. Her focus of treatment of her arthritis was cure based. In addition, despite her personal beliefs, she felt that medication was the only thing that would help to "fix" the problem. In this sense, she had given up her personal control to the illness and felt that only external things such as her doctor or medications could achieve her treatment goal, which was ultimately a cure for her illness.

Profile of the Self-Manager

Individuals interviewed indicated that to be a successful self-manager required a certain personality and mindset. Self-managers tended to have an independent personality. They were disciplined and motivated people, and they tended to have a positive outlook on life. They believed there was something they could do to help, and their focus tended to be on their abilities rather then their limitations. Furthermore, they felt that the self-management approach helped them to keep this positive outlook and focus, as it gave them increased responsibility and control over their health and health care.

Successful self-managers did not view their arthritis as a limitation and felt that it was controllable. These individuals believed it is important to accept the illness in order to live with it successfully.

Self-managers had a tendency to participate in self-directed learning activities; they were information seekers and enjoyed learning. They believed that it was important for them to take an active approach in the treatment of their arthritic condition.

Self-managers were independent and tended to like to do things for themselves. They had a take-charge personality and found ways to solve problems they faced and help themselves. They had the ability to adjust to change easily.

Self-managers believed that it is important to care for oneself. In addition they felt it was their responsibility to manage their own health and health care. As such, they felt they were well suited to the self-management approach as it allowed them to take responsibility for their care. In addition, self-managers like to have control over their life, which was consistent with the self-management approach.

Self-managers believed that education was one of the most important components of managing their health as it gave them the knowledge and the skills required to manage their illness. They felt that this gave them more control and power. In addition they felt that education helped them to accept their illness. They felt that process-oriented education was the best way to learn self-management.

Self-managers believed in focusing on managing their illness on a day-to-day basis rather than focusing on a cure for their chronic arthritis. They stressed the importance of health education and teaching others how to accept and manage the consequences of their illness.

Results of the study indicate characteristics of individuals who are not successful self-managers. Participants felt that individuals with low motivation and effort to self-help are not suited to the self-management approach. They suggested individuals who lack discipline and who have a dependent personality would not do well with self-management.

As participants indicated the importance of taking responsibility for their health care, they indicated that those who do not take responsibly for their care are not successful self-managers.

Participants suggested that individuals who have a negative outlook on life and who view their arthritis as a limitation are not suited to the self-management approach. In addition, individuals who believe that the illness is beyond their control would not fare well with self-management.

Participants felt that individuals who are dependent upon motivation that is external to themselves are not suited to self-management. In addition, they indicated that individuals who take a passive rather than an active approach to managing their health would be poor self-managers. Similarly, individuals who are focused on finding a cure to fix them, rather than managing the illness on a daily basis and focusing on their abilities, are not successful self-managers.

This concludes the presentation of the findings of the study. The next chapter serves to discuss the findings in relation to the literature and to present conclusions and recommendations for the study.

CHAPTER FIVE: DISCUSSION, CONCLUSIONS, AND IMPLICATIONS

This is a study of the self-management approach to health education and the treatment of chronic health problems. The main objective of the study was to gain a better understanding of the self-management approach to the treatment of chronic arthritis. Qualitative and quantitative research methods were used with individuals who had participated in an arthritis self-management program. The numerous findings of the study were very insightful in consideration of the questions posed at the outset of the research project. In addition, the results highlight the complexity surrounding the self-management approach. The focus of this final chapter is to discuss the findings of the study in light of the related literature. In addition, conclusions and implications for research and practice will be outlined.

Discussion

Results of the study suggest that the arthritis self-management program under investigation caused an overall increase in the participants' self-efficacy to manage their arthritic condition. Although the data from the small-scale quantitative part of the study are not generalizable across all self-management programs, these findings are consistent with Lorig and Gonzalez (1992), where a large scale quantitative study reported enhanced self-efficacy as a result of the Arthritis Self-Management Program. As such, findings of this study support the theory that self-management health education programs result in increased levels of self-efficacy to self-manage a chronic

illness.

Although overall self-efficacy was enhanced during the course, only two out of the three subscales showed significant increases when comparing pre- and postcourse levels of self-efficacy. The two sub-scales which showed a significant change focused on measuring the participants' confidence to perform self-management behaviors and to manage the disease in general. The one subscale which did not show significant change in participants levels of self-efficacy after the course measured the participants' confidence to achieve outcomes. Together, this indicates that individuals felt more confident to perform self-management behaviors and manage the disease in general, but were not confident that these behaviors would lead to a change in outcomes, such as a reduction in the symptoms associated with their arthritis, or the ability to complete household chores despite health-related problems.

In reviewing the literature, there is no obvious explanation for the significance of change in the first two subscales and lack of significant change in the third subscale. It could be hypothesized that generally individuals have a more difficult time gaining confidence to produce outcomes associated with the self-management approach. For example, achieving successful outcomes to many individuals may mean a total resolution of symptoms or the ability to complete their normal activities of daily life without any functional limitations. In the case of chronic diseases, these expectations are unrealistic as there is no known cure and symptoms do commonly limit function. Therefore, high levels of self-efficacy to achieve outcomes (such as total abolishment of symptoms) may have seemed more challenging to participants than gaining confidence

in the other two subscales, as their outcome expectations may have been unrealistic. Therefore, heightened confidence in their abilities to perform self-management behaviors and self-manage the disease in general may be more easily attained than the confidence to achieve the outcomes desired by participants. Additional research is necessary to determine if this discrepancy among the subscales is common among all individuals who participate in arthritis self-management programs. A large-scale quantitative study would be useful to differentiate among the subscales used in the study and to determine if it is a common for individuals with chronic disease to build confidence in some aspects of self-management more easily than others.

The findings of the study indicate a precourse discrepancy and a postcourse congruence between the scores of the visual analogue scale (VAS) and the Lorig self-efficacy scale. The precourse measurement of the VAS produced high levels of self-efficacy across all participants, whereas the Lorig scale scored only 4 participants with high self-efficacy and 3 participants with low self-efficacy. This suggests that precourse either some participants underestimated their self-efficacy when scoring the Lorig scale or overestimated their self-efficacy when scoring the visual analogue scale. Considering that the Lorig scale has been shown to be reliable and valid (Lorig et al.,1996) and the VAS was modified specifically for this study, the latter explanation is more probably the case.

Postcourse results revealed congruence between the scales. For example, the scores from the Lorig scale and the VAS were consistently high for 6 individuals and consistently low for 1 individual. These findings suggest that individuals were more

realistic judges of their self-efficacy when scoring the visual analogue scale postcourse in comparison to precourse. Therefore, individuals may be better able to judge their self-efficacy to self-manage their arthritis after taking an arthritis self-management program.

To suggest that the visual analogue scale is an adequate measure of self-efficacy to self-manage a chronic condition is undetermined. A large-scale study would be required to determine if the two scales used in this study could be used interchangeably.

Subjective course outcomes were described by participants during the interview process. Four participants had excellent outcomes, 2 participants had good outcomes, and 1 participant had poor outcomes. The positive outcomes described by participants and listed in Chapter Four are consistent with the benefits of self-management programs as described by Gibson (1991) and Lorig and Gonzalez (1992), such as enhanced personal control, self-concept, and overall life satisfaction, decreased symptoms associated with the illness, and improved attitudes and beliefs surrounding the illness. These findings suggest that, overall, the self-management program studied was beneficial to individuals attempting to learn to self-manage their chronic arthritis.

Individuals with good outcomes suggested that they would have benefited more from the program if they have taken it closer to the time of diagnosis. They felt that the program would have been very helpful to them just after diagnosis, at a time when they had a lot of questions that were not easily answered by their health care professionals due to the professionals' time restraints.

Participation in the program sooner after diagnosis saves the individual with the illness time in searching for information independently and attending numerous appointments with health care professionals. Furthermore, it saves health care professionals valuable and costly time as patients are less dependent upon their health care providers. For instance, in taking a self-management health education program, participants receive the information and support required to manage their illness and in turn are less reliant on the health care system.

Participants indicated that outcomes may be enhanced by early educational intervention. Therefore, the issue of early educational intervention in the case of chronic illnesses must be addressed by health educators and health care professionals who refer their patients to self-management programs. Marketing and advertising strategies must focus on early access to programs, as this may be when participants can benefit most, and in turn enhance the potential for positive course outcomes. Furthermore, successful outcomes within programs may then lead to reduction in health services utilization and, therefore, less financial and personnel strain on the health care system.

Participants also suggested a variety of other ways to enhance course outcomes. First was increasing the size of the class to allow for more group discussion and sharing-both of which were felt to be very important processes of learning self-management. In the case of the groups studied, course enrollment was extremely low. According to the ASMP leader's manual, Lorig (1995) suggests that ideal enrollment of the course is between 10 and 15 people. Unfortunately, both courses studied had only

5 and 8 participants respectively. Considering the interactive nature of the course curriculum, these low enrollment numbers may have influenced the outcomes of the course. For example, small class size may have limited the diversity in the class, and therefore participants would have fewer individuals to relate to and learn from.

These findings can be further explained using the adult education literature. Group sharing and peer learning are valued within the field of adult teaching and learning. For example, Cranton, (1992) indicates that the learner comes to the learning environment with valuable knowledge and experience from which others can learn. Further, these experiences are used as an instructional resource for group learning. Lack of class diversity within self-management programs results in fewer experiences among individuals and therefore fewer learning resources. In this sense, individuals who had only good outcomes from the course may have had excellent outcomes if enrollment in the programs had been greater.

These findings are an excellent example of the interconnectedness of the many aspects surrounding self-management health education. For instance, lack of participation resulting in low course enrollment may result in poor course outcomes. Poor course outcomes have the potential to hinder participation in programs as the outcomes of programs are viewed as less valuable amongst those in the medical community and society at large. Conversely, increased numbers of individuals who participate in programs may influence course outcomes positively due to enhanced sharing and discussion. Positive outcomes can in turn promote the program through

word of mouth or outcome statistics, enhancing participation and self-management, resulting in decreased health services utilization.

Individuals also suggested that outcomes could be enhanced if there were more time. They felt that more time would have allowed for more group interaction in the form of sharing, discussion and support. Furthermore, they felt it would have helped to enhance the group's cohesiveness and in turn promote an atmosphere of trust. Again, like the importance of class size, these findings point to the relationship between self-management health education and adult education theory. For example, participants valued their peers' opinions and enjoyed learning from others. As described by Cranton (1989), adults come to the learning situation with previous experience, which can be a valuable resource for learning. As such, the techniques used in adult teaching and learning are experiential. Learning strategies such as problem solving, group work, case studies, role playing simulation exercises, and discussion are all processes that require time and in some cases more time than content-oriented education that lacks student interaction and participation. Health educators must consider the time necessary for these process-oriented techniques when developing curriculum for self-management programs.

Similarly, individuals with chronic arthritis indicated a need for peer support and suggested that they learn best in a comfortable and safe learning environment. Individuals interviewed felt that increased time would have allowed them to get more comfortable with others in the course, promoting an open learning environment and resulting in more sharing and support. As described by Brookfield (1986) and Knowles

(1984), adults learn best in a climate where they are physically and psychologically safe. Again, the link between health education and adult education is evident. As such, adult education theory and practice are an asset to health educators and should be considered in program planning and implementation.

Many individuals suggested that ongoing support after the course would have been helpful to them in self-managing their arthritis. Findings of the study indicate the importance of support in learning self-management and coping with the emotional consequences associated with the disease. As such, individuals who valued the support they received in the program may have desired ongoing support after completion of the program. This finding is in direct opposition to much of the literature conducted in the quantitative longitudinal studies of the ASMP which indicate that support after the program was not necessary to maintain positive health outcomes (Lorig & Holman, 1989).

The benefits of support in learning self-management are very apparent in many aspects of this study and as such cannot be ignored. Although course outcomes may not be enhanced by ongoing support after the program as indicated by the self-management literature (Lorig & Holman, 1989), ongoing support may be beneficial to individuals in ways that can be measured only subjectively rather than by objective research methodologies. Further qualitative study may be helpful in determining how ongoing support would be beneficial to individuals who had participated in a self-management health education program. In addition, studies that focus on identifying

what type of ongoing support individuals would benefit from most would be helpful for health educators who are developing programs.

To summarize, 6 participants of the course reported positive outcomes as a result of the course. The positive course outcomes indicate the success of self-management approach to health education and illustrate how individuals with chronic arthritis can benefit from participating in self-management health education programs. Despite these positive outcomes, early intervention, class size, class time, and ongoing support were suggested as ways to enhance outcomes. Health educators must consider these factors when developing and implementing self-management health education programs for individuals with chronic illnesses.

The individual in this study who had poor outcomes was unsure as to the reason why the course was not helpful to her. Although she understood the concepts behind the course, she was not able at the time of the course to motivate herself enough to follow through with what she had learned. As such, she felt that she was unsuccessful at self-managing her arthritic condition and therefore felt her course outcomes were poor. This finding supports the literature which challenges the traditional assumptions in health education that increased knowledge results in changes in health behavior and, in turn, health outcomes. For example, if this particular individual's knowledge were tested, it might be high, yet the educational intervention did not result in changes in behavior or outcomes. These findings are in agreement with earlier studies (Lenker, et al., 1984; Lorig, et al. 1984) that dispute the common

assumption in health education research that changes in health-related knowledge lead to changes in health behavior and health outcomes.

A number of themes regarding reasons for poor outcomes arose from the insights of individuals who participated in the study. Findings suggest that an individual's personality, beliefs, attitudes, and abilities are primary determinants of course outcomes and successful adoption of the self-management approach in the treatment of chronic disease. Furthermore, results indicate that an individual's current emotional state is another factor that can prevent successful self-management of a chronic illness. These determinants of outcomes of self-management health education programs will now be discussed in detail.

First, results of the study indicate that certain characteristics are necessary to be successful at self-managing chronic arthritis. Likewise, individuals without these particular characteristics tend to have difficulty in using the self-management approach. The profiles of a successful and unsuccessful self-manager are summarized in Table 9.

Successful self-managers tend to be individuals who have a positive outlook on life and do not view their arthritis as a limitation. They are independent people who like to have control of their lives. They see their arthritis as controllable and just another thing in their life to manage. Similarly, they tend to be self-directed and individuals who are interested in helping themselves. Successful self-managers tend to have good problem-solving abilities and are able to adapt to change easily. They are individuals who believe that their health and health care are their own responsibility

Table 9

Characteristics of the Self-Manager

The successful self-manager	The unsuccessful self-manager
➢ Independent ➢ Self-disciplined ➢ Motivated to self-help ➢ Self-directed learners ➢ Information seekers ➢ Problem solvers ➢ Easily adapt to change ➢ Positive outlook ➢ Desire for a fulfilling life ➢ Take-charge personality ➢ Importance of having control over your life and the illness ➢ Abilities focused ➢ Reliant on internal sources for motivation and treatment of the illness ➢ Illness can be a limitation but it is controllable ➢ Active approach to management and treatment of the illness ➢ Acceptance of the illness ➢ Importance of education in management of the illness ➢ Management focused ➢ Self-responsibility for own health and health care ➢ Consistent with the self-management model	➢ Dependent ➢ Lack of discipline ➢ Lack of motivation to self-help ➢ Lack of self-direction in learning ➢ Poor problem-solving ability and/or motivation ➢ Less able to adapt to change ➢ Negative outlook ➢ Belief that their illness is beyond their control ➢ Lack of get up and go ➢ Feels life is controlled by the illness ➢ Limitations focused ➢ Denial and fear of the illness ➢ Reliant on external sources for motivation and treatment of the illness ➢ Lack of responsibility for health and health care ➢ Passive approach to management and treatment of the illness ➢ Cure focused ➢ Consistency with the compliance model

and feel that health care professionals play a very small part in the treatment of their condition. They are individuals who are focused on managing their arthritic condition and their health, rather than focused on curing their illness. Successful self-managers are individuals who have accepted their illness and view it as just another thing to manage in their lives.

Unsuccessful self-managers tend to have nearly the opposite profile. They tend to have a negative outlook on life. They believe their arthritis is a limitation and a handicap that significantly restricts their lives and well-being. They see their condition as hopeless and are dependent upon others and medications for help. They have low levels of motivation and take a more passive approach to the treatment of their arthritis. Poor self-managers tend to view their health care professionals as responsible for their health and health care. They have poor problem-solving abilities and do not adjust to change easily. They tend to be focused on finding a cure that will alleviate all of their symptoms, rather than managing the illness on a daily basis. Individuals who are unsuccessful at self-managing have not accepted their illness emotionally and view the illness as controlling their lives. In addition, they tend to look for things that are external to themselves to solve the problems they are having with their illness.

When comparing the literature with the characteristics of successful and unsuccessful self-managers, it is apparent that individuals who are successful self-managers and are well suited to the self-management model have characteristics similar to those of self-directed learners as described by Knowles (1984), Cranton (1992) and Brookfield (1986). For example, like self-directed learners, self-managers are motivated

to learn, independent in the decision-making, and responsible for learning about their health and health care. These findings suggest that individuals who are successful at self-management may also be successful at self-directed learning. Furthermore, these findings indicate that the self-directed learning literature may be a useful adjunct to the self-management literature.

Individuals with characteristics of those who are not successful at self-management of their chronic illness seem to fit in well with more traditional models of health care and health education, such as the compliance model. For example, unsuccessful self-managers tend to take a more passive approach to treatment and are more dependent on their health care providers to make decisions for them. They take little responsibility for their health and health care, giving up their personal control to the health care provider. These traits fit well with the role of the patient in the compliance model of health education and the traditional medical model of health care.

Individuals who are unsuccessful at self-management tend to be focused on finding a cure for their disease, with little interest in preventing progression of the disease or the management of its consequences over time. Again, this outlook is consistent with more traditional models of medicine as they are based in acute disease in which the ultimate goal of treatment is a cure. As treatment is cure focused, the concept management of chronic disease is foreign and irrelevant. It is apparent from these results that individuals who are suited to and conditioned within the compliance model of health education may not be suited to the self-management approach to

health education, despite the numerous benefits to individuals with chronic disease. Ironically, it is the health care system that is theoretically trying to help these individuals that in some cases is promoting feelings of dependency, hopelessness, and helplessness that these individuals are experiencing.

In consideration of the profiles of the successful and unsuccessful self-manager, Friere's philosophy of education is particularly relevant. The banking model of education as described by Freire (1970), like the compliance model, is consistent with the profile of an unsuccessful self-manager. For example, in these oppressive models, patients are required to be passive recipients of care and instruction, lacking the development of critical thinking and problem-solving skills. Therefore, individuals with chronic disease remain passive in their health care and dependent upon health care professionals to care for them. Without developing the skills and abilities to self-manage their chronic disease, individuals in this model remain helpless and lack the knowledge and motivation required to cope with their illness.

Findings of the study suggest that the unsuccessful self-manager does not have the motivation or ability to follow through with self-management or self-help strategies. Freire's (1970) philosophy is based on the notion that all individuals want to help themselves. Despite this, unsuccessful self-managers do not seem to want to self-help. Considering Freire's philosophy, it may be the oppressive nature of the compliance model, with which these individuals identify most closely, that is preventing them from living their life free of the restraints of the disease. Specifically, the dominant culture is not easily overcome and some individuals may be reluctant to

depart from a condition that they know and are comfortable with, in spite of the fact that it may be oppressive and controlling. In this sense, it may be that, although all individuals have the ability to be successful self-managers, some are stuck in a state of oppression which does not allow them to accept their illness and self-manage their own health and health care.

All people can live in an nonoppressed state. Freire (1970) indicates that, given the tools, individuals living in a state of oppression can become liberated from that oppression. This suggests that individuals who are not self-managers have the potential to become liberated and learn to manage themselves rather than be dependent upon others. Given the proper tools to self-manage, individuals may be enabled to depart from the oppression that blocks the individual from helping themselves and accepting the illness and, in turn, successful self-management. Therefore given the tools to overcome the oppression that prevents an individual from managing their illness can result in a transition in the individual's thinking patterns and behavior whereby they are liberated to self-manage. In the case of self-management health education, it may be that education gives some individuals the increased self-efficacy to self-manage which changes their outlook, beliefs, and behaviors, enabling and empowering them to take control and self-manage.

The compliance model of health education is characterized by an imbalance of control and responsibility for one's health and health care between the patient and provider. The self-management model empowers individuals to take increased responsibility for their own health and health care, promoting a feeling of self-control.

Self-management enables individuals to manage the consequences of their illness independently or, in some cases, interdependently with health care providers and their communities.

The findings of this study support the literature that indicates that self-management patient education is well suited to many individuals with chronic illnesses. Despite the benefits of self-management programs, not all individuals have successful course outcomes. Results of the study indicate that specific characteristics of an individual can influence their health outcomes when participating in self-management health education programs. Therefore this study suggests that individuals may inherently be prone to excellent or poor course and health outcomes depending on their individual personality, beliefs, attitudes, and abilities.

The emotional impact of a chronic illness and how one deals with the emotions associated the illness is also a determinant of course outcomes. Findings of the study revealed a variety of complex emotions and emotional stages associated with living with chronic arthritis. Common emotions of individuals who are diagnosed with chronic arthritis include: fear, confusion, uncertainty, anger, frustration, depression, denial, and hopelessness.

Results of the study suggest that individuals with chronic arthritis transition through the negative emotions associated with being diagnosed with arthritis and ultimately begin to emotionally accept their health condition. Furthermore, individuals with chronic arthritis work through the negative emotions associated with being diagnosed with the illness at different times and at different rates.

Acceptance of the illness is critical to successfully living with a chronic disease. For example, participants of the study agreed that acceptance of all aspects of the chronic illness is the key to living with the symptoms that the illness presents. Therefore, positive course outcomes like successful self-management are realized through acceptance of the illness. Likewise, lack of acceptance of the illness can result in poor course outcomes.

The transition from feelings like fear and denial to acceptance of the illness is mirrored in the literature surrounding death and dying. Kubler-Ross, in the 1969 edition of On Death and Dying, identified five psychological stages that terminally ill patients often experience as they approach death: denial, anger, bargaining, depression, and acceptance. These stages are similar to the feelings that individuals with chronic arthritis expressed. Although the emotions described in the results of this study were not specifically slotted into successive stages, the early emotions are consistent with denial, anger, and depression, and acceptance of the illness tended to be the emotional goal of individuals with chronic arthritis. The similarities to Kubler-Ross's model are apparent, and as such the emotional impact of a chronic disease may be considered similar to that of a grieving process. In this sense, individuals who are diagnosed with a chronic illness may be grieving the loss of life as they once knew it and attempting to face their new life with a chronic illness.

Similar to the results of the current research, Kubler-Ross (1969) suggested that the stages of death and dying are only a guideline, and many individuals go through these stages at different times and at different rates. Furthermore, as patterns vary

from person to person, many individuals with arthritis do not fit easily into the specific stages identified by Kubler-Ross. Similarly, it is important to understand that these stages are neither continuous, linear, or final. For example, individuals may move in and out of these various emotions according to the progression of symptoms and their ability to cope with the challenges of everyday life.

Although the results of this study do not point specifically to the particular psychological stages as outlined by Kubler-Ross (1969), they may serve as an outline for further research and practice into the emotional impact of a chronic illness. As such, the results of this study serve only to guide the health educator and researcher in understanding the emotional effects of chronic arthritis and the adoption of the self-management approach.

Results of the study indicate that an individual's emotions surrounding the chronic disease can impact course outcomes. Individuals who have accepted their illness tend to be better able to cope with it, and in turn are better able to adapt to the self-management approach. Conversely, individuals who have not accepted their illness and who are stuck in negative emotions such as fear, denial, and anger have a more difficult time self-managing their condition. As such, individuals who have not accepted their illness tend to be challenged to self-manage their condition, and therefore are prone to poor outcomes from self-management health education programs.

The transition to acceptance of the illness is critical to successful living and management of chronic disease. Individuals interviewed felt that support from others,

including their peers and health care professionals, was critical in the transition from fear and denial to acceptance of chronic arthritis. Support from others in the ASMP through group discussion and interaction gave the participants the opportunity to face some of the distressing emotions they were feeling associated with the illness. Furthermore, it validated their feelings, which in some cases allowed them to release the negative emotions associated with their illness, and in turn helped them to accept their health condition.

In addition to support, individuals felt that education also helped them to accept their illness. They felt that gaining knowledge of the disease and the disease process gave them increased understanding and control over their illness, which was empowering. Furthermore, education gave them the tools they needed to accept the illness. As suggested by Freire (1970), education can empower an individual and give them the tools needed to overcome their oppressed state and give them back their power to live their lives with individual, free choice. Self-management health education can help individuals to accept their illness and enable them to take control of their lives and their health and health care. Therefore, self-management health education can have a liberating effect on individuals with chronic disease.

Living with a chronic disease in the traditional medical model can retard the progression from emotions such as denial and fear to acceptance. Patients may feel that the support and education that are critical to acceptance and successful self-management of chronic disease are lacking in the compliance model. For example, as the educational process in traditional health education tends to be a one-way

transmission of knowledge, individuals are not partners with their health care professionals, jointly assessing their learning needs. Furthermore, the absence of a working partnership, characterized by a lack of trust, respect, and mutual support and sharing, does not promote acceptance of the illness and in turn self-management.

The traditional medical model is based on curative treatment for acute disease. In the case of chronic disease, the absence of a cure can leave medical professionals without definitive answers for their patients. Solutions to the problems that individuals with chronic disease face are unavailable, and as such many medical professionals disbelieve their patients' reports of symptoms and deny the diagnosis of any serious illness. Denial on the part of the medical professional promotes denial by the patient. Furthermore, the medical community influences society's beliefs about health and health care and as such, their attitudes about chronic illness set the norms of society. This mass denial on the part of the health care provider, the patient, and society at large is oppressive to individuals with chronic illnesses. It promotes feelings of helplessness and dependence, rather than empowerment and independence, and is destructive to individuals who are attempting to live a fulfilling life with a chronic disease rather than being controlled by others or the illness itself. Therefore, the acute care medical model has the potential to hinder an individual from acceptance of their illness and in turn from self-managing their health and health care.

Results of the study suggest that lack of emotional acceptance of chronic arthritis can impair learning self-management. This finding mirrors the adult education literature, which suggests that the learner must be ready to learn. For

example, individuals with poor outcomes from self-management health education programs may not be experiencing a teachable moment as described by Knowles (1984), as they may not have accepted the illness. This suggests that individuals with chronic illnesses must be ready physically, intellectually, and emotionally to learn self-management. As such, if an individual has not accepted their illness, they may not be emotionally ready to learn, and thus they will be less likely to successfully self-manage. In this case, the health educator must focus on the learning needs of each individual and help them to accept their illness, in order to move forward and manage it.

The importance of acceptance of the chronic illness in individuals who have chronic arthritis is apparent. It was evident in the interview process that individuals with positive course outcomes had accepted their illness to the extent that it allowed them to live a fulfilling life while managing their arthritis, rather than being controlled by it. Statements made by one individual with poor course outcomes suggested that she had not accepted her illness, which in turn influenced her ability to self-manage and affected her course outcomes. The emotional impact of chronic arthritis, like the inherent traits, beliefs, attitudes, and abilities of individuals, can influence the course outcomes of arthritis self-management programs. In conclusion, to ensure the success of arthritis self-management health education programs, it is critical to address the emotional impact of chronic illnesses.

To summarize, results of the study suggest that the self-management program caused an overall increase in participants' self-efficacy. Furthermore, the subjective course outcomes suggest that the course was beneficial. Specifically, 6 individuals

reported positive course outcomes and 1 participant of the study had poor course outcomes. Determinants of course outcomes, such as timing of educational intervention, class size and time, ongoing support, individual beliefs, personality, attitudes and abilities, and the impact of emotions on course outcomes have been discussed. The discussion of the results will now focus on the relationship between the course outcomes and the individuals' self-efficacy to self-manage their chronic arthritis.

The findings of the study are consistent with Lorig's work surrounding the relationship between self-efficacy to self-manage chronic arthritis and course outcomes. In this study, high levels of postcourse self-efficacy to self-manage an arthritic condition were consistent with good and excellent course outcomes. Conversely, low levels of postcourse self-efficacy were associated with poor course outcomes. These findings mirror the results found in the self-management literature. Lorig and Gonzalez (1992) reported that favorable health outcomes were found to correlate much more strongly with the individual's levels of perceived self-efficacy to cope with the different consequences of a chronic arthritic condition. Similarly, Stretcher (1986) found that the higher the perceived efficacy to cope with chronic arthritis, the less pain, depression, stress, and disability experienced, and the greater the prevention of future joint impairment. The findings of this study complement the large body of available research that supports the role of self-efficacy in teaching and learning within the health education environment (Davis, Busch, Lowe, Taniguchi, & Djkowich, 1994; Le Fort, Gray, Donald, Rowat, & James, 1998; Lorig & Holman, 1989; Lorig, et al., 1989; Moore, 1990; Stretcher, 1986; Taal, Rasker & Wiegman, 1996).

Considering the various results of the study, the relationship between course outcomes and self-efficacy could also be influenced by the inherent characteristics of each participant and their emotional state at the time of participation. In summary, two distinct patterns emerged. First, individuals who had positive course outcomes and high levels of self-efficacy were also individuals who fit the profile of a successful self-manager and had emotionally accepted their chronic illness. Conversely, the individual who had poor course outcomes and low self-efficacy fit the profile of an unsuccessful self-manager and had not made the emotional transition from denial and fear to acceptance. These patterns encompass the many different aspects of the self-management approach to health education. Furthermore, these findings are valuable additions to the self-management literature as they explain why many individuals do not participate in self-management health education programs and why those who do participate do not all benefit equally.

Analysis of the self-efficacy scores pre- and postcourse suggest that three possible phenomena occurred during the self-management program. Four participants with high self-efficacy precourse had slight increases in their self-efficacy to manage postcourse, 2 individuals who had low precourse self-efficacy had high postcourse self-efficacy, and 1 individual remained with low self-efficacy to self-manage their arthritis postcourse. Discussion of these findings highlights the relevance of these three distinct groups in relation to participation and outcomes of self-management programs.

High precourse self-efficacy of 4 individuals to self-manage their arthritis was further enhanced postcourse. The high precourse levels of self-efficacy to self-manage

their chronic arthritis suggests that these individuals had the confidence and abilities to self-manage their health and health care before the course. This heightened confidence to self-manage may have predisposed the individuals to participate in the self-management program. For example, individuals with high self-efficacy were shown to have the characteristics common to successful self-managers, which included a self-directed personality. It may be that individuals with high self-efficacy precourse are already successful self-managers and as such self-directed learners. In this case, individuals may be more likely to participate in programs, as it is in their nature to take part and help themselves. Similarly, as indicated by Williams et al. (1998), participants of health education programs are generally those who are inherently interested in their health and well-being. Therefore, these results suggest that high levels of self-efficacy to self-manage a chronic illness may be a predisposing factor for individuals to participate in self-management health education programs.

Results of the study indicate that the individuals with high self-efficacy both pre- and postcourse had positive course outcomes. The self-management literature indicates that high baseline levels of self-efficacy are responsible for the positive course outcomes (Lorig and Gonzalez 1992). For example, individuals with high self-efficacy may adopt self-management strategies presented in the course more easily due to their high self-confidence in their abilities. As such, the high baseline levels of self-efficacy may be the primary reason for the positive course outcomes in this group of participants.

Individuals with high levels of self-efficacy before the course are well suited to the self-management approach to health education. For example, they have enough inherent confidence to self-manage their illness that the knowledge and skills presented in the self-management courses are easily applied. As such, these individuals are valuable participants in self-management health education programs as they benefit from programs with good health outcomes. In addition, these individuals can be motivating and inspiring to others in the group who have less inherent confidence to self-manage.

Individuals with high precourse self-efficacy are especially important in process-oriented programs like the ASMP, as the curriculum focus is group learning and interaction. Modeling, peer feedback, persuasion, and reinterpretation of symptoms are efficacy-enhancing strategies that are described by Bandura (1986) and are incorporated as educational processes of the ASMP. Therefore, individuals with high baseline levels of self-efficacy to self-manage serve as excellent models for individuals with low baseline levels of self-efficacy. Similarly, through the group interaction, individuals with low levels of self-efficacy can enhance their efficacy by feedback and coaching from their peers with high baseline confidence to manage their arthritis.

The second phenomenon that occurred when comparing pre- and postcourse levels of self-efficacy to self-manage an arthritic condition was a transition from low levels to high levels of self-efficacy. The particular individuals (Subjects 2 and 5) in the study who changed from a low self-efficacy score to a high self-efficacy score are of great importance. In comparison to the rest of the participants, these two individuals

showed the greatest change in their self-efficacy during the course. It was these individuals who made a significant transition from one state of mind and confidence level to another. In addition, their attitudes and outlook seemed to change from being negative to positive. The transition that occurred in these individuals' outlook, attitudes, and emotional state as a result of the course are consistent with Bandura's self-efficacy theory. For example, enhanced levels of self-efficacy result in improved health behaviors, motivation, thinking patterns, and emotional well-being (Bandura, 1986). In this sense, the change in outlook, attitudes, and emotional state during the course may have been a result of an increased confidence to manage their arthritis. Therefore, individuals felt they had more control over their health and well-being and they were better able to manage the consequences of their illness, resulting in enhanced health outcomes. This pattern between self-management health education and course outcomes is illustrated in Figure 1 in Chapter One and is consistent with self-efficacy theory (Bandura, 1986).

Individuals with low baseline levels of self-efficacy who participated in a self-management health education program were successful in making the transition to adopting the self-management approach resulting from enhanced levels of self-efficacy. As suggested in the self-management literature, this enhanced self-efficacy in turn resulted in good course and health outcomes. This finding supports previous work by Lorig and Gonzalez (1992) which indicated that course outcomes depend not only the baseline levels of perceived self-efficacy but also the growth of that perceived self-efficacy during the course. These individuals are the most profound success stories of

the self-management programs, as the educational intervention empowers the individual to take control of their lives with the illness, rather than allowing the illness to control their lives. Individuals who make this transition as a result of the course are very important members of self-management programs as they can inspire others to make the same transition from denial and fear to acceptance and successful living with the illness.

The second group characterized by a transition from low to high levels of self-efficacy are an important group to target when promoting chronic disease health education programs. It is these individuals who may be able to benefit most from the effects of self-management health education. For example, these individuals may transition from poor quality of life, low satisfaction with their health care, and high dependence on the health care system to successfully self-managing their health independently or, more likely, interdependently with their health care providers. This shift to a more self-reliant existence can reduce health care expenditures and in turn the financial strain on the health care system.

Research is necessary to identify the specific characteristics and experiences of individuals who transition from low to high self-efficacy to self-manage their chronic arthritis. Increased understanding of this particular group may assist health care providers and health educators in helping individuals to make the transition from low to high levels of self-efficacy to self-manage their chronic arthritis, and likewise from compliance to self-management.

In summary, results of the study indicate that all individuals with high self-efficacy postcourse also had favorable course outcomes. These findings are consistent with Lorig's work that indicates that the course outcomes of self-management programs are related to the individual's baseline self-efficacy and with the growth of the self-efficacy during the course. In this case 4 out of the 6 individuals with positive outcomes had high baseline self-efficacy, whereas the 2 individuals with low self-efficacy prior to the course had significant growth of their self-efficacy as a result of the course.

The third trend in changes in self-efficacy that resulted from the course was that of the individual who started and remained with low levels of self-efficacy to manage her chronic arthritis. This individual also reported poor course outcomes. Results of the study indicate that some individuals may characteristically not be ideally suited to the self-management approach. As described by the study participants, some individuals may not have a self-management personality or outlook. Again, a summary of the characteristics of successful and unsuccessful self-managers was discussed earlier in this chapter and is outlined in Table 9.

The findings of the study are consistent with the literature that indicates that individuals characterized by low self-efficacy generally have poor outcomes from taking self-management programs (Lorig and Gonzalez 1992). Despite poor outcomes, it is important not to exclude this third group from participating in self-management programs. First, some individuals with low baseline levels of self-efficacy transition to high self-efficacy as a result of the course and become successful self-managers with

excellent course outcomes. It would be difficult to differentiate between individuals who could potentially have significant gains in their confidence to self-manage, and as such have good course outcomes, from those who do not.

As suggested by Knowles (1984), adult learning depends on the individual's readiness to learn, and certain life events can trigger the learning. As such, individuals who are successful in making the transition from low self-efficacy to high self-efficacy with associated positive course outcomes may have experienced, as described by Knowles (1984), "a teachable moment". In this sense, the individual is triggered by some experience or series of experiences to begin to make the transition from compliance to self-management.

The individual who had poor course outcomes and low self-efficacy despite the self-management course seemed to remain in a state of dependence on others to help her. For example, comments she made during the interview suggested that she was looking for other people or other things to motivate her. The move from dependence in the compliance model of health education to independence in the self-management model is similar to the shift from more traditional models of education to self-directed learning. As suggested in the self-directed learning literature, adults have a deep psychological need to be self-directed and the move from dependence to self-direction can occur very slowly. Cranton (1989) indicates that although adult learners strive for independence, they are prone to be dependent learners in circumstances when they are in unfamiliar situations, if they have low self-esteem, or if they have never experienced self-directed learning. As such, individuals become independent learners or self-

managers of their illness at different times and at different rates depending on their life experiences and level of self-confidence. Therefore, individuals who are not successful in self-managing their chronic illness, despite participating in a self-management program, may not be ready at that particular time to make the shift from dependence to independence.

Similarly, in consideration of the literature on the stages of chronic disease, the individual may have different responses to the arthritis self-management program depending on the stage of the disease. Van Eijk and DeHann (1998) indicated that learning self-management is most effective in the diagnostic and establishment phases of a chronic illness (See Appendix A). It is during these phases that individuals are most responsive to learning about their illness and how to manage it. In the words of Knowles (1984), these particular stages may be where there is the greatest likelihood of a "teachable moment". Van Eijk and DeHann further suggest that self-care education in later stages of chronic illness is less effective, as patterns and expectations have been set in previous stages. The different stages of chronic disease and the associated readiness to learn within those stages is critical to understand when evaluating course outcomes from self-management health education programs. Again, this is consistent with the findings of this study that suggest the importance of early educational intervention in the case of chronic disease. Furthermore, timing of the program and readiness of the individual to learn are critical points to reflect upon in the development of health education and self-management programs.

Despite poor outcomes, individuals with low pre- and postcourse self-efficacy are important members of self-management health education programs, as they bring diversity to the group. For instance, through their experiences these individuals may inspire others in the program to learn, resulting in increased self-efficacy to manage their arthritis. Conversely, others in the group may influence and educate them just enough so they can start to self-manage and make informed decisions about their health care. Considering these findings, individuals with low levels of self-efficacy and poor health outcomes may actually be contributing to the success of the program.

The results of the study indicate that some individuals do not benefit from self-management health education programs. These findings are useful to health educators as they can validate their practical experiences. Furthermore, it gives health educators some insight as to the reasons for the lack of success with some of their course participants. Greater understanding of the characteristics of individuals who do not seem to benefit from self-management health education programs may help educators and researchers to study this group with the focus to improve upon curriculum, teaching methods, and outcomes of the programs.

Results of the study provide insight into the process of learning to self-manage a chronic illness. Participants interviewed described the learning processes that helped them to learn to self-manage their chronic arthritis. Not surprisingly, strategies which were most helpful in learning self-management in many ways mirrored the adult education literature.

Most individuals felt that activities that involved group interaction such as discussion, problem solving, support, and sharing were essential in learning self-management. These can be described as experiential learning strategies and are consistent with adult education theory and practice. Collectively, these learning formats are conducive to learning self-management as they allow individuals to take a more active role in the learning, which as indicated by Knowles (1984), is the preference of the adult learner as it makes the learning more meaningful.

The participatory learning processes described as helpful to participants also provide a supportive atmosphere for learners. Support is a major theme that emerged from this study that is helpful for individuals in accepting their chronic illness and is essential in learning to self-manage. Similarly, the value of a supportive atmosphere is cited in the adult education literature as important so that learners can feel at ease and are able to express themselves freely (Knowles, 1984). Furthermore, Caffarella (1994) indicates that adults learn best when they are supported and can support their peers.

These learning processes that assisted individuals in learning were consistent with the philosophy behind the self-management model, as they promote the individuality of the learner. In contrast to the banking model of education and the compliance model of health education, this type of learning demands that the learner identify and find solutions to their problems according to their own personal values and expectations. As such, this type of learning is consistent with the underlying philosophy of the self-management model of health education, which requires the individual to take increased responsibility for their learning and their health and health

care. Furthermore, this type of learning fosters the development of problem solving and critical thinking and reflection skills, which are essential for the success of the self-management of one's health and health care.

It was very apparent from the findings of the study that self-management is best learned through peer learning. Individuals interviewed felt that learning through others and the lay instructor facilitated their learning. In addition, individuals felt that the more they could relate to another learner, whether it be the lay instructor or a fellow participant, the more they could learn from them. These are examples of modeled behavior assisting individuals to learn self-management. Contracting was also suggested by many participants as helpful in learning self-management. These findings support Bandura's (1977) self-efficacy theory and in turn the basis for the ASMP course curriculum. For example, learning through efficacy-enhancing and experiential learning strategies helped to increase the participants' confidence to self-manage their arthritis and in turn enhanced health outcomes. Therefore, the findings of this study suggest that efficacy-enhancing strategies assisted individuals in learning to self-manage their chronic arthritis. These findings directly support the previous research by Lorig and Gonzalez (1992) and Bandura (1986), indicating that increasing self-efficacy can enhance self-management behaviors and as a result course outcomes.

The results of the study highlight the importance of the learning process in self-management health education for individuals with a chronic illness. These findings are consistent with Lenker et al. (1984) who suggested the importance of educational

process in learning self-management. When reporting the results of a study focusing on an arthritis self-management health education program, Lenker et al. (1984) wrote:

> The results of this study again reinforce the importance of educational process. This often is underplayed in an attempt to cover all necessary patient-education content. Process is especially important in dealing with such noncognitive areas as depression, social support and control (p. 71).

The findings of the current study are consistent with the self-management literature. Participants valued learning processes such as group discussion and support. Further, these processes helped them to increase their self-efficacy and learn self-management.

The information age was highlighted in the findings of this study as one of the reasons for lack of participation in health education programs. For example, participants of the study suggested that lack of participation in programs was a result the massive amounts of health information available. In today's society, health information is easily accessible to the general public. Contrary to the compliance model of health education, the concept of freedom of information through technology supports the self-management model and similarly self-directed learning. As such, many individuals in society who are naturally self-managers or self-directed learners may be using different sources to help them manage their chronic arthritis, independent of their health care providers or health education programs in general.

Self-directed learning through the Internet or educational materials such as books or journals is an excellent way to gain knowledge pertinent to a chronic illness. Although this is an excellent way to keep informed about one's health and health care,

it is evident from the results of this study that it is not the best way to learn self-management skills. As discussed above, results of the study suggest the importance of educational process in learning self-management. Self-directed learning using resources such as the Internet is isolating and lacks dialogue and personal interaction. Although the individual can choose what they want to learn, this type of learning is similar to the banking model of education, as it demands memorizing information rather than open dialogue and group reflection. As such, the individual can repeat facts about their illness but lacks the problem-solving and critical thinking abilities that are developed in more group-oriented, interactive education.

Roter (1987) suggests that health education which is devoid of interaction and dialogue is nondirective and fails, as individuals may misinterpret or misuse information gained. Research surrounding the use of the Internet as a health education tool must consider the importance of educational process. The findings of this study further reinforce the importance of human interaction in developing the critical thinking and problem-solving skills necessary for successful self-management of one's health.

Findings of the study suggest that self-management health education is effective in helping individuals cope with their chronic arthritis. Furthermore, findings suggest reasons for lack of participation in programs as well as reasons for lack of beneficial outcomes for some individuals. Considering the results of this study and the state of our current health care system, health education can no longer be thought of as a nice extra to the treatment of chronic illnesses. Rather, health education is necessary for

the effective care of individuals with chronic illnesses and the survival of our current health care system.

Individuals who participated in the study had strong beliefs about problems they saw with the current health care system. Furthermore, they suggested solutions to these problems. When comments made by participants were linked back to the related health care literature, it was evident that the problems identified were consistent with the traditional medical model of health and the compliance model of health education. Furthermore, the solutions to these problems were congruent with the self-management model.

Individuals interviewed felt that commonly doctors did not believe their patient's symptoms associated with the chronic illness, and therefore many individuals with chronic illnesses had a difficult time getting a diagnosis. These results suggest the lack of acceptance of chronic illnesses in society and in the traditional medical model which is based on acute disease. For example, in the traditional medical model the doctor is expected to "fix" the patient, which could be feasible in the acute care setting, yet in the case of chronic illnesses this is in many cases impossible. In order to avoid feelings of professional failure, the doctor denies the chronic illness and in turn, the patient's voice is muted. As discussed earlier, this denial on the part of the health care professional can result in patient denial and lack of care of the disease. In addition, with the lack of care, the unmanaged symptoms are exacerbated and the patient returns to the health care professional for answers. This can result in a continuous cycle, causing much frustration on the part of the patient and the health care provider.

Furthermore, it is a costly cycle to the health care system, as frustration and denial on both sides of the relationship cause increased referrals to additional specialists to find a solution to the problem rather than focusing the health care dollars on teaching the patient the skills that will help them to manage the problem interdependently.

Participants agreed that lack of time with their health care professionals was another area of concern. They suggested that they felt rushed and did not have enough time to talk with their health care professionals. These individuals saw the importance of education in the treatment of their chronic disease and felt that lack of time did not allow for adequate education. These results support the literature which indicates the importance of educating individuals about their illness and ways to manage it. Furthermore, a solid educational program may have an impact on participants that lowers their dependence on their health care providers for answers to their questions about their disease. Again, studies have shown that self-management education of chronic arthritis is not only empowering to the individual but also cost effective (Lorig et al., 1993).

A discrepancy between the beliefs of patients and physicians that was presented in the results section was the belief that physicians are medication focused, whereas their patients are not. The imbalance between the beliefs of the patient and provider in the traditional medical model is apparent. In addition, as the traditional medical model tends to be cure focused, many patients consult with their doctors with the intention of receiving a cure. Medication is then prescribed, as it is in some cases the physician's only tool to care for their patients. Adoption of the self-management

model in the health care provider's professional practice would not only better suit the needs of individuals living with chronic illness, but would take some of the pressure associated with cure-focused care off the health care provider.

Successful self-managers made many suggestions as to their ideal relationship between a patient with chronic arthritis and a health care professional. They suggested the importance of open communication and mutual decision making that are consistent with the self-management model. They believed that their health care provider played the role of diagnostician and prescription and referral source only, rather than that of treatment provider. In addition, individuals felt that it was their role to take an active part in the treatment of their illness. Again, this is in agreement with the self-management model, as the individual's health care is primarily their own responsibility.

The one individual who was not successful using the self-management approach in the treatment of her chronic arthritis had beliefs that were consistent with the traditional medical model and the compliance model of health education. For example her focus was cure based and she felt dependent upon her health care provider to "fix" her. Furthermore, she did not seem able to motivate herself to take responsibility for her own health and health care, which is required in the self-management model. These findings suggest that in the self-management model individuals are motivated from an internal source, whereas in the more traditional models of health the individual requires things external to themselves such as medication or their health care provider to motivate and treat their illness.

There are distinct differences between the self-management model and the compliance model of health education. The results of this study confirm the basic difference in these philosophies. Further, they point to the benefits of the self-management model in the treatment of chronic illnesses. Clearly, not all individuals with chronic health conditions are suited to the self-management approach, despite its advantages over the compliance model. The research points to reasons for lack of participation and poor outcomes within self-management health education programs. In addition, this study further clarifies the relationship between self-efficacy theory and participation and outcomes from self-management health education programs.

Conclusions

Arthritis self-management programs are effective in teaching individuals with arthritis to self-manage their health and health care. Overall, most individuals benefited from the course, with positive course outcomes and heightened self-efficacy to self-manage their arthritis. One individual scored low levels of self-efficacy to manage her arthritis after the course and did not benefit from the program, as she stated she had poor course outcomes.

The results of the study suggest that there are a variety of factors that influence course outcomes. For example, the participant's personality, beliefs, attitudes, and abilities and the participant's degree of emotional acceptance of the illness are both major determinants of course outcomes. Other factors that influenced group outcomes included: the size of the course, the timing of participation within the

course, the amount of time allotted for the course, and ongoing support after the course.

Results of the study suggest that reasons for lack of participation in self-management health education programs are similar to the factors that determine course outcomes. First, the results suggest that individuals may not participate in programs due to their interests, personality traits, and beliefs about the illness. Similarly, emotions such as fear and denial may stop an individual from participation in programs. Other reasons for lack of participation include lack of awareness of programs and increased availability of health information in society.

The study found that adult teaching and learning principles are critical in learning to self-manage a chronic illness. Furthermore, efficacy-enhancing strategies as described in self-efficacy theory are also helpful in motivating individuals to adopt the self-management approach.

The incompatibility between the treatment of chronic illness in the traditional medical model of health and the compliance model of health education is apparent. Participants of the study indicated that many of their complaints with the current health care system and the medical profession are consistent with the limitations of the compliance model in the treatment of chronic disease. Furthermore, the suggestions made by individuals are consistent with the self-management model of health care and health education. As such, a shift to the philosophical approach of health care known as self-management from more traditional models is necessary for the well-being of individuals with chronic illnesses and the sustainability of the health care system.

Recommendations for Future Research

The results of the study may serve as the impetus for future research in the field of health education. Findings of the study revealed a significant change in two of the three subscales: self-efficacy to perform self-management behaviors and to manage the disease in general. The third subscale, which measured self-efficacy to achieve outcomes, did not significantly change for this group. There is no obvious reason for the discrepancy among the sub-scales of Lorig's self-efficacy scale. Future research is needed to investigate if these findings are consistent among all individuals who are attempting to adopt the self-management approach in the treatment of their chronic illness. In addition, research which investigates the reasons for the lack of change in the third subscale may be warranted. This research could include testing the hypothesis generated in this study that it is more difficult for individuals to achieve high levels of self-efficacy to achieve outcomes.

The two scales used in the study were the VAS and the Lorig self-efficacy scale. The findings of the study suggest that these scales were congruent postcourse but inconsistent precourse. Further research is warranted to compare and contrast these two scales in an attempt to better understand the findings of this study. In addition, further research is necessary to determine if these scales can be used interchangeably in health education research and practice.

Findings of the study suggest that timing of an educational intervention is of the utmost importance for individuals with chronic illnesses. Further study that specifically addresses the notion of appropriate timing for participation in health

education is warranted to validate the findings of this study. In addition, developing a better understanding of the relationship between the stages of chronic disease and timing of the program would prove to be useful for health educators who are developing and promoting programs.

Three different phenomena occurred during the self-management program studied. Four individuals who had high baseline levels of self-efficacy remained high upon course completion. Two individuals with low baseline levels of self-efficacy had high levels of self-efficacy upon course completion, and one individual remained with low levels of self-efficacy despite the self-management health education program. Further research is indicated to study each of these three phenomena independently and collectively. Characteristics of the individuals in each group may help to improve upon curriculum, teaching methods, and course outcomes. In addition, the fourth possible phenomenon that could occur in self-management health education programs is a change from high levels of self-efficacy precourse to low levels of self-efficacy postcourse. This phenomenon did not occur during the course studied and is highly unlikely, as a goal of the course is to increase self-efficacy to self-manage, yet this possibility still exists.

Findings of this study suggest that an individual's baseline levels of self-efficacy to self-manage their chronic illness may be a predisposing factor in choosing to participate in self-management health education programs. Further research is indicated to investigate in more detail the relationship between baseline levels of self-efficacy and participation in courses. A study that investigates the normal level of self-

efficacy across individuals who do not participate in health education programs in comparison to individuals who do choose to participate would assist in understanding if self-efficacy is correlated to participation.

Results of the study suggest that poor course outcomes of self-management health education programs are related to an individual's personality, attitudes, beliefs, and abilities, in addition to their emotional state and attitudes towards the illness. Further research is indicated to investigate in detail the reasons for poor course outcomes to confirm the findings of this study.

Lack of participation in self-management health education programs may be the result of increased availability of health information. For instance, individuals may be learning about their health and wellness through sources such as books, medical journals, or the Internet. The findings of this study suggest the importance of learning processes such as group discussion, interaction, and support in learning to self-manage a chronic illness. Individuals who are learning about their illness in isolation may not be gaining knowledge, which may not lead to changes in their health behaviors and outcomes. Considering the popularity of the other methods of study such as self-directed learning on the Internet, further research into the differences between knowledge-based learning and process-based learning is indicated.

Lack of enrollment in self-management health education programs is apparent. This study suggests factors that may prevent individuals from participating in programs. Further research into the reasons for lack of enrollment may help to verify the results of this study and enhance enrollment in these programs. Considering the

ASMP is a program that is available internationally, it may be useful to investigate how other courses with sufficient enrollment in programs are promoting and marketing the program.

Lack of acceptance of chronic illness en masse would result in significant strain on the health care system. As such, it is critical to study the phenomenon of the transition for negative emotions to acceptance of the illness. Furthermore, investigating in more detail the triggers that help individuals to transition to acceptance would be helpful for health educators and health care professionals, as strategies to nurture the transition could be developed. Furthermore, research into this transition may explain other questions like: do individuals remain in acceptance of their illness or is it an ongoing process as the illness progresses or changes in life occur? For example, could a successful self-manager become an unsuccessful self-manager due to changes in their life or changes in their disease?

Arthritis self-management health education has been shown to be a cost-effective adjunct to primary care in the treatment of chronic arthritic conditions (Lorig et al., 1993, 1999; Mazzuca et al., 1999). As our government is trying to be fiscally responsible, research into the cost savings, specifically for the Ministry of Health in Ontario, is critical to promoting self-management programs, health education, and the self-management model.

Implications for Practice in the Field of Health Education

The results of the study point to a variety of implications for practice for health educators and health care professionals alike. First, early educational intervention is critical to the success of self-management health education. Results of the study suggest that self-management programs are most beneficial to individuals who are recently diagnosed with chronic arthritis. This is consistent with the literature surrounding stages of chronic disease which suggests that education is critical for patients in the early stages of the chronic illness when they are most impressionable and can develop habits and behaviors that are essential to managing their health condition. Promotion of health education programs must stress the importance of early educational intervention to ensure that the course is a good use of time and resources for the provider, and beneficial to the individual with the chronic illness.

Like early educational intervention, the results of the study indicate the importance of considering class size and length of class time when developing self-management health education programs. Considering the nature of the course curriculum and teaching strategies, adequate class participation and time are essential to ensure positive course outcomes. Adequate advertising and marketing of programs is necessary to recruit more participants to programs to enhance participation in courses.

Considering the importance of support in managing a chronic illness, ongoing support after programs should be more available to individuals who have participated in programs. Although there are many support and interest groups available through

the Arthritis Society and other community groups, time must be taken during the courses to promote participation and utilization of support services.

Results of the study suggest that the emotional impact of a chronic illness significantly influences an individual's ability to self-manage their chronic health condition. It is critical that health educators are aware of the impact of emotions and are trained to help individuals work through those emotions. Denial and fear are common emotions that block acceptance and in turn self-management of a chronic illness. Therefore, the health educator must have the ability to work with individuals to support and facilitate them in dealing with these negative emotions and transitioning to acceptance of the illness.

The profiles of successful and unsuccessful self-managers developed from the findings of the study can be helpful to the health educator. Understanding that personality traits, worldview, and skills set can be factors in an individual's ability to self-manage helps the health educator to comprehend why some individuals are successful at self-management whereas others are not. Furthermore, by identifying some of the characteristics of a successful self-manager, the health educator has some identifiable goals to strive for when teaching self-management.

The results of the study suggest that within self-management health education programs there may be individuals who have good course outcomes and others who do not. Findings of the study suggest reasons for poor course outcomes which may validate their professional experiences and help them to devise learning strategies

which may help them to facilitate learning in individuals who have low confidence to self-manage their arthritis and potentially course outcomes.

Adult education theory and practice are useful tools for the health educator. Results suggest that many of the experiential learning techniques used in adult education are useful in learning self-management. Health educators must be aware of the adult education literature and trained in using the facilitation techniques commonly used by adult educators. Similarly, the use of efficacy-enhancing strategies is particularly useful in teaching self-management health education. Using a variety of techniques aimed to increase participant's self-efficacy to self-manage seemed to help to motivate individuals in self-managing their chronic arthritic condition. Like adult education, health educators must be comfortable with self-efficacy theory and using the efficacy-enhancing strategies in developing course curriculum and within the teaching and learning environment.

All together, the results from the study surrounding learning self-management indicate the importance of educational process. Although knowledge building is important in health education, the results of the study suggest educational processes based in adult education and self-efficacy theory, which involved group interaction, problem solving, support, and sharing, are critical in learning self-management. Health educators must consider the time, staffing, and participation requirements of process-oriented education when developing and conducting health education programs.

Results of the study suggest that the traditional model of health education is no longer suitable for the treatment of chronic illnesses. Results confirm that self-management health education is more suited to individuals with chronic health problems as it allows them to take increased responsibility for their health and health care-which they welcome. Health educators must be aware of the difference between the compliance model of health education and the self-management model when developing health education programs. Furthermore, considering the financial crisis of our health care system, self-management health education plays a critical role in the management of chronic health problems.

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Appendix A

Stages of Chronic Disease

STAGE 1 CRISIS:

Pre-diagnostic phase

: Complaints and symptoms prompt a visit to a health care professional
: Individual is under significant tension and uncertainty until a final diagnosis is made.

Diagnosis phase**

: Diagnosis indicates that a chronic disease will influence the rest of the individual's life
: The individual must learn to accept living with a chronic disease and find a new sense of balance in relation to the disease.
: Successful living with the illness depends on the extent to which the disease causes an infringement upon the individual's life.

Establishment phase**

:The disease should be somatically and psychosocially well established and treated.
: The individual must adapt to living with the illness.
: Behavioral patterns are developed which help the individual cope with the disease.
: Important for self-care strategies be learned in this phase.

STAGE 2 CHRONICITY:

Stabilization phase**

:The individual gradually finds a way of living with the illness.
: Low involvement of health care professionals especially in situations where the individual is able to cope well using self-care.
: The individual sees their health care professional for check-ups to monitor the illness in order to prevent complications or comorbidity.
: Daily functioning is scarcely affected, mainly due to the considerable self-care ability of the patient.

Progression phase**

:The chronic disease can no longer be kept under control.
: Increasing frequency of the complaints and consultation with health care professionals.
: Slight increase in impairments and decrease in general health status, individuals are still relatively independent.

Complication phase

: Complications related to the illness occur.
: More intensive contact with health care professionals and home care is required.
:Individual is now more considerably dependent on their social network and professional help.
: Still considerable potential for self-care, yet more dependence on others for care.

STAGE 3 TERMINAL STAGE:

Pre-terminal phase

: Many chronic illness eventually result in considerable dependence on family, friends and health care professionals.
: Individual is often confined to home, chair or bed and normal functions are no longer possible.
: Death counseling is initiated.

Death

: Days preceding the death of the individual; parting is a central theme.
: Need for increased support from social systems and health care professionals

Post-terminal phase

: Mourning process

**Indicates the stages where self-management health education is most important.*

Adapted from Van Eijk, et.al. (1998)

Appendix B

Copy of Ethics Review Acceptance

Brock University

Senate Research Ethics Board **Extensions 3205/4315, Room C315**

FROM: David Butz, Acting Chair
Senate Research Ethics Board (REB)

TO: L. Adams, Physical Education
Wendy Campbell

FILE: **99-285, Campbell**

DATE: **May 17, 2000**

The Brock University Research Ethics Board has reviewed the research proposal:

Experiences of Older Adults and the Self-Management of Chronic Arthritis

The Research Ethics Board finds that your revised proposal conforms to the Brock University guidelines set out for ethical research.

***Accepted as revised.**

Please note: Changes or Modifications to this approved research must be reviewed and approved by the committee. Please complete form #5 - ***Request for Ethics Clearance of a Revision or Modification to an Ongoing application for Ethics Review of Research with Human Participants*** and submit it to the Chair of the Research Ethics Board. You can download this form from the Office of Research Services or visit the web site:
http://www.BrockU.CA/researchservices/mainethicsformpage.html

DB/ge

Appendix C

Letter to Participants

May 30, 2000.

Dear

I received your name and address from Mary Dolene at the Arthritis Society of Canada, as you are a participant in the upcoming Arthritis Self-Management Program (ASMP). I am writing to you to inform you of the research study that is being conducted on the ASMP.

I am a physiotherapist with special interests in arthritis and the treatment of chronic disease. I am currently enrolled in the Master's of Education program at Brock University. As part of my research I will be conducting a study on the effects of the self-management approach in the treatment of chronic arthritis. I hope to have between 10 and 15 participants of the Arthritis Self-Management Program take part in this study.

On the first day of the upcoming course, I will spend a few minutes towards the end of the session with you to more formally introduce myself and my research. Specifically, I will introduce the purpose and the details of the study, answer any questions you may have and invite you to participate. It is important for you to understand that participation in this study is voluntary and not a requirement of the Arthritis Self-Management Program. Furthermore, if you choose to participate, you may withdraw from the study at any time and for any reason without penalty.

This study has been designed so that it will in no way interfere with the objectives, timing or instruction of the ASMP. If you choose to participate in this study, you will first be required to fill out two short questionnaires on the first and last days of the program. Second, during a private interview session after the course is completed you will be asked to share your point of view regarding a variety of topics including your health and health care, how you cope with your arthritis and your thoughts regarding the educational program.

I thank you for your time and consideration, and look forward to meeting with you at the course!

Sincerely,

Wendy Campbell, BSc.P.T.

Appendix D

Research Study Information Sheet

Title: " Experiences of Adults and the Self-Management of Chronic Arthritis"

Researcher: Wendy Campbell, BSc.P.T.
Department of Education
(905)-849-8190

Lorne Adams, Ph.D.
Department of Physical Education
(905)-688-5550, extension 3382

Why: To gain a better understanding of the self-management approach to health education.

To gain better understanding of the most effective means for conducting health self-management programs.

To gain insight as to why some individuals with chronic conditions participate in self-management programs and why others do not.

Who: The study will be conducted during the Arthritis Self-Management Program over the next few months. The study will require 10 to 15 individuals to participate in the project.

When: The study will start on the first day of the course and end approximately 2 weeks after the course is completed.

Where: Completion of the questionnaires will take place at the location of the ASMP. Individual interviews upon completion of the course will take place at the location most convenient to the participant.

What: Participants will be required to fill out two questionnaires on the first day and the last day of the course. The questionnaires should take between 5 and 10 minutes to complete. After the course is completed, participants will be individually interviewed by the researcher for approximately 45 minutes. The focus of the interview is to gain the participant's perspective surrounding the self-management of chronic conditions.

Appendix E

Informed Consent Form

Brock University, Department of Education

Title of Study: "Experiences of Adults and the Self-Management of Chronic Arthritis"

Researcher: Wendy Campbell

Faculty Advisor: Dr. Lorne Adams, Department of Physical Education
Phone: (905)-688-5550, extension 3382

Name of Participant: _____

I understand that this study in which I have agreed to participate will involve discussing my beliefs about the arthritis self-management program and the self-management approach of treating chronic illnesses.

I understand that my participation in this study is voluntary and that I may withdraw from the study at any time and for any reason without penalty.

I understand that there is no obligation to answer any question or participate in any aspect of this project that I consider invasive.

I understand that there will be no payment for my participation.

I understand that all personal data will be kept strictly confidential and that all information will be coded so that my name is not associated with my answers. I understand that only the researcher's named above will have access to the data.

I am aware that I will be answering questions on two questionnaires at the beginning and at the end of the Arthritis Self-Management Program. I am aware that upon completion of the ASMP, the researcher will privately interview me for approximately 45 minutes at the location of my choice. I understand that the interview will attempt to determine my beliefs about the self-management approach of treating chronic illnesses. I realize that it is necessary for the researcher to audiotape the interviews for analysis at a later date.

I understand that Ms. Campbell will contact me one time by mail in the months following the interview to present me with a summary of her findings.

I understand that Ms. Campbell is conducting these interviews to complete the requirements for her Masters thesis in Education.

Participant Signature _____ Date_____

This study has been reviewed and approved by the Brock Research Ethics Board. (File # 99-285, Campbell).

If you have any questions about your participation in this study, you can contact me (Wendy Campbell) at my home number (905)-849-8190 or Lorne Adams at (905) 688-5550, extension 3382.

Feedback about the use of the data collected will be available by December, 2000 in the library at Brock University. A written explanation will be provided for you upon request.

Thank-you for your help! Please take a copy of this form with you for your future reference.

I have fully explained the procedures of this study to the above volunteer participant.

Researcher Signature_____ Date_____

Appendix F

General Information Form

Name: _____ *Age:*_____

Type of Arthritis: _____

*Other medical conditions:*_____

_____

Current Medications (type and dosage): _____

_____

When were you diagnosed with your arthritic condition? _____

_____

By whom were you diagnosed with an your arthritic condition? _____

_____

How would you rate your current activity level (circle one answer only):

A) Not active (I exercise less than 20 minutes once weekly)

B) ***Slightly active*** *(I exercise for 20 minutes or more, 1-2 times per week)*

C) ***Active*** *(I exercise for 20 minutes or more, 2-3 times per week)*

D) ***Very active*** *(I exercise for 20 minutes or more, 3-4 times per week)*

E) ***Extremely active*** *(I exercise for 20 minutes or more, 4-5 times per week)*

Appendix G

Questionnaire #1: The Visual Analogue Scale

Questionnaire # 1: The VAS Self-Score

VAS: Self-Efficacy

I am interested in learning how you feel about your personal abilities to manage your arthritic condition. Take a moment to think about how well you feel you are able to manage the symptoms of your arthritis condition.

Please mark an "**X**" on the line below to describe your level of confidence that you have the ability self-manage your arthritis.

Low confidence to self-mange arthritis _____ High confidence to self-manage arthritis

Appendix H

Questionnaire #2: The Self-Efficacy Scale

Self-Efficacy to Perform Self-Management Behaviors

SE Exercise Regularly

We would like to know **how confident** you are in doing certain activities. For each of the following questions, please circle the number that corresponds to your confidence that you can do the tasks regularly at the present time.

How confident are you that you can...

1. Do gentle exercises for muscle strength and flexibility three to four times per week (range of motion, using weights, etc.)?

Not at all confident	1	2	3	4	5	6	7	8	9	10	Totally confident

2. Do an aerobic exercise such as walking, swimming, or bicycling three to four times each week?

Not at all confident	1	2	3	4	5	6	7	8	9	10	Totally confident

3. Exercise without making your symptoms worse?

Not at all confident	1	2	3	4	5	6	7	8	9	10	Totally confident

SE Get Information About Disease

We would like to know **how confident** you are in doing certain activities. For each of the following questions, please circle the number that corresponds to your confidence that you can do the tasks regularly at the present time.

How confident are you that you can...

1. Get information about your disease from community resources?

Not at all confident	1	2	3	4	5	6	7	8	9	10 Totally confident

SE Obtain Help From Community, Family and Friends

We would like to know **how confident** you are in doing certain things. For each of the following questions, please circle the number that corresponds to your confidence that you can do the tasks regularly at the present time.

How confident are you that you can...

1. Get family and friends to help you with the things you need (such as household chores like shopping, cooking or transport)?

Not at all confident	1	2	3	4	5	6	7	8	9	10 Totally confident

2. Get emotional support from friends and family (such as listening or talking over your problems)?

Not at all confident	1	2	3	4	5	6	7	8	9	10 Totally confident

3. Get emotional support from resources other than friends or family, if needed?

Not at all confident	1	2	3	4	5	6	7	8	9	10 Totally confident

4. Get help with your daily tasks (such as housecleaning, yard work, meals, or personal hygiene) from resources other than friends or family, if needed?

Not at all confident	1	2	3	4	5	6	7	8	9	10 Totally confident

SE Communicate With Physician

We would like to know **how confident** you are in doing certain activities. For each of the following questions, please circle the number that corresponds to your confidence that you can do the tasks regularly at the present time.

How confident are you that you can...

1. Ask your doctor things about your illness that concern you?

Not at all confident	1	2	3	4	5	6	7	8	9	10 Totally confident

2. Discuss openly with your doctor any personal problems that may be related to your illness?

Not at all confident	1	2	3	4	5	6	7	8	9	10 Totally confident

3. Work out differences with your doctor when they arise?

Not at all confident 1	2	3	4	5	6	7	8	9	10 Totally confident

Self-Efficacy to Manage Disease in General

SE to Manage Disease in General

We would like to know **how confident** you are in doing certain activities. For each of the following questions, please circle the number that corresponds to your confidence that you can do the tasks regularly at the present time.

How confident are you that you can...

1. Having an illness often means doing different tasks and activities to manage your condition. How confident are you that you can do all the things necessary to manage your condition on a regular basis?

Not at all confident 1	2	3	4	5	6	7	8	9	10 Totally confident

2. Judge when the changes in your illness mean you should visit a doctor?

Not at all confident 1	2	3	4	5	6	7	8	9	10 Totally confident

3. Do the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?

Not at all confident	1	2	3	4	5	6	7	8	9	10 Totally confident

4. Reduce the emotional distress caused by your health condition so that it does not affect your everyday life?

Not at all confident	1	2	3	4	5	6	7	8	9	10 Totally confident

5. Do things other than just taking medication to reduce how much your illness affects your everyday life?

Not at all confident	1	2	3	4	5	6	7	8	9	10 Totally confident

Self-Efficacy to Achieve Outcomes

SE Do Chores

We would like to know **how confident** you are in doing certain activities. For each of the following questions, please circle the number that corresponds to your confidence that you can do the tasks regularly at the present time.

How confident are you that you can...

1. Complete your household chores, such as vacuuming and yard work, despite your health problems?

Not at all confident	1	2	3	4	5	6	7	8	9	10 Totally confident

2. Get your errands done despite your health problems?

Not at all confident 1	2	3	4	5	6	7	8	9	10 Totally confident

3. Get your shopping done despite your health problems?

Not at all confident 1	2	3	4	5	6	7	8	9	10 Totally confident

SE Social/Recreational Activities

We would like to know **how confident** you are in doing certain activities. For each of the following questions, please circle the number that corresponds to your confidence that you can do the tasks regularly at the present time.

How confident are you that you can...

1. Continue to do your hobbies and recreation?

Not at all confident 1	2	3	4	5	6	7	8	9	10 Totally confident

2. Continue to do the things you like to do with friends and family (such as social visits and recreation)?

Not at all confident 1	2	3	4	5	6	7	8	9	10 Totally confident

SE Manage Symptoms

We would like to know **how confident** you are in doing certain activities. For each of the following questions, please circle the number that corresponds to your confidence that you can do the tasks regularly at the present time.

How confident are you that you can...

1. Reduce your physical discomfort or pain?

Not at all confident	1	2	3	4	5	6	7	8	9	10	Totally confident

2. Keep the fatigue caused by your disease from interfering with the things you want to do?

Not at all confident	1	2	3	4	5	6	7	8	9	10	Totally confident

3. Keep the physical discomfort or pain of you disease from interfering with the things you want to do?

Not at all confident	1	2	3	4	5	6	7	8	9	10	Totally confident

4. Keep any other symptoms or health problems you have from interfering with the things you want to do?

Not at all confident	1	2	3	4	5	6	7	8	9	10	Totally confident

5. Control any symptoms or health problems you have so that they don't interfere with the things you want to do?

Not at all confident	1	2	3	4	5	6	7	8	9	10	Totally confident

SE Control/Manage Depression

We would like to know **how confident** you are in doing certain activities. For each of the following questions, please circle the number that corresponds to your confidence that you can do the tasks regularly at the present time.

How confident are you that you can...

1. Keep from getting discouraged when nothing you do seems to make any difference?

Not at all confident	1	2	3	4	5	6	7	8	9	10	Totally confident

2. Keep from feeling sad or down in the dumps?

Not at all confident	1	2	3	4	5	6	7	8	9	10	Totally confident

3. Keep yourself from feeling lonely?

Not at all confident 1	2	3	4	5	6	7	8	9	10	Totally confident

4. Do something to make yourself feel better when you are feeling lonely?

Not at all confident 1	2	3	4	5	6	7	8	9	10	Totally confident

5. Do something to make yourself feel better when you are feeling discouraged?

Not at all confident 1	2	3	4	5	6	7	8	9	10	Totally confident

6. Do something to make yourself feel better when you feel sad or down in the dumps?

Not at all confident 1	2	3	4	5	6	7	8	9	10	Totally confident

Appendix I

Sample Interview Questions

Characteristics of Participants

1. How did you hear about the program?
2. Why did you choose to participate?
3. You have had arthritis for _____ did this time affect your decision to participate?
4. Do you know anyone with arthritis who would benefit from the program? Do you think they would participate?
5. Can you think of reasons why others might not participate?
6. Can you think of ways we can get others with arthritis to participate?

Outcomes

1. Do you feel the course has helped you in terms of:

    pain and physical discomfort
    energy level and or fatigue
    general health/activity level
    ability to cope with emotions associated with arthritis
    relationship with your doctor

2. How are you now able to cope with your condition that you were not able to do before?
3. Do you feel you will be able to maintain the positive outcomes and if so for how long?
4. How could the course have been more helpful to you?
5. To better suit your needs, in what ways would you have changed it.
6. What is your next step or long term goals in the management of your arthritis?

Participants Beliefs

1. How do you feel about having arthritis?
2. How has having arthritis changed your life?
3. Do you see it as a limitation or a handicap?
4. How do you view your life as a person with arthritis?
5. What do you think the best approach to treatment is for arthritis?
6. In what ways to you think differently about arthritis since the course?
7. Have you participated in health education in the past? If so, what was it and was it helpful?
8. Would you like to participate in another program, if so what kind?
9. Do you think health education plays an important role in the treatment of arthritis?
10. How would you describe your relationship with your doctor(s)?
11. What do you think the ideal relationship should be?
12. What do you see as your role within that relationship?
13. How large of a role does your doctor play in your health care?
14. How much help do you feel you need from your doctor to manage your arthritis successfully? Do you get your needs met?

SE

1. Was the course helpful to you? If so why? If not why not? Break it down like did you like the contracting, feedback, discussion, information, meditation?
2. What about the course itself did you like? What did you like about the learning process? Did the self-management approach to health education work well for you? What did you like about it, what did you dislike about it?
3. Did you feel you learned how to manage your arthritis better in the course? If so what part of the course helped you to learn these skills?
4. What about the course did you dislike? What parts so the course would you do differently? If you could how would you have changed the course so that it would have better met your needs?